Using trauma as a lens to explore the experience of mothering a very premature infant in the first year after hospital discharge

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Statement of Authorship

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Abstract

Approximately 60,000 premature babies are born in England every year (Office of National Statistics ONS, 2017). Survival rates of babies weighing 800g and over have risen to 90% (WHO, 2018) resulting in an increasing number of mothers parenting very premature babies. Understanding the experiences and needs of these mothers is important for identifying and providing the most appropriate support. This is therefore an important area of developing research.

The aim of this research is to understand how the trauma of a very premature birth affects the experience of mothering these infants in the first year after hospital discharge. A purposive sample was collected, comprising 8 mothers who had given birth between 28 and 32 weeks' gestation within the previous 3-5 years. 8 face-to-face, semi-structured interviews were conducted and Interpretative Phenomenological Analysis was applied to analyse the transcribed data.

The results elicited 7 superordinate themes: 'The second set of horror'; 'The isolation of limbo'; 'Attachment to the NICU'; 'Feeling like a mother came later'; 'Bonding in the shadow of the threat of loss'; 'Mourning an intangible loss' and 'Mothering in the wake of trauma'. These themes capture how the trauma of the very premature birth and the experience of the neonatal intensive care unit (NICU) influenced the way these women were able to relate to their babies, take care of them, bond with them, and develop their identity as a mother. The emergent themes are inherently existential and are explored from an existential perspective.

Key words

Mothering Very premature infant Existential Psychotherapy Post-NICU Trauma

Birth trauma

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1. Introduction

This topic is of personal interest to me as my daughter, now 8, was born at 29 weeks' gestation. After two long, traumatic months on the neonatal intensive care unit (NICU), her homecoming was indeed a celebration, but we also felt terrified and alone. I was already a psychology student and it was natural to me to reach out for therapy, but I noticed at the time that no one else had mentioned anything to us about emotional support and no one had prepared us for the emotional reactions we might experience over the months to follow. I thought back to the diverse group of mothers I had met on the NICU and wondered how other mothers without my background and understanding of psychology might have coped. I wondered what their experience had been like and this was the birth of my research question.

As a doctoral student in psychology I recognised the effects of our trauma and knew that therapy would offer good support, but it proved difficult to find support that suited our needs. We felt that we needed to speak to someone who understood our journey in order to help us work through our experience, but I was unable to find any specialised resources providing emotional support for parents of premature infants. I also recognised that accessing support would require a concerted and proactive effort on my part.

It is therefore through my own experience of mothering a preterm infant and my journey in search of support that I developed an interest in this phenomenon. These experiences have encouraged me to explore this area from a professional perspective to investigate how others might experience this journey and to consider the need for specialist support services for preterm parents.

As an existential psychotherapist my work is informed by the existential phenomenological approach that emphasises the importance of understanding the individual's unique experience. This research has brought these principles into action and allowed me to explore this phenomenon from both a theoretical and empirical perspective. My discussion will be informed by an existential perspective on the

findings, drawing on relevant existential literature and existential psychotherapy principles.

The World Health Organisation (WHO) defines premature babies as those “born alive before 37 weeks of pregnancy are completed” (WHO, 2018). Three sub-categories are defined based on gestational age: extremely preterm (less than 28 weeks) very preterm (28 to 32 weeks), moderate to late preterm (32 to 37 weeks). Every year an estimated 15 million babies are born premature and the number is rising (WHO, 2018). Currently, around 7.3% of live babies born in the United Kingdom each year are premature, with approximately 60,000 of these babies born in England (Office of National Statistics (ONS), 2017). Survival rates of babies with a birth weight of 800g and over have risen to 90%.

With the number of global premature births and survival rates rising yearly, this phenomenon has become an important area of research (WHO, 2018). Rising survival rates have led to an increasing number of mothers parenting very premature babies. Understanding the experiences and needs of these mothers is important for identifying the best provision of support and this is therefore an important area of developing research. Medical care for premature babies and support for their families cost the NHS millions of pounds annually (WHO, 2018). Research in this area is therefore also important for ensuring the most efficient allocation of scarce financial resources, both in the UK and globally.

Becoming a mother is invariably a major life stressor, both physically and psychologically (Miller and Sollie, 1980; Arnold-Baker, 2015). In the event of a very premature birth this stress is compounded by the mother’s likely experience of shock, fear and trauma, both physically and psychologically, due to the unexpected traumatic birth circumstances and the fragile, unpredictable condition of her new-born baby (Howland, 2007). This is usually followed by the emotional and exhausting experience of the baby’s stay in the NICU, which can range in duration from a few days to a few months, depending on the gestational age and health of the baby (Madden, 2000).

When an otherwise healthy very premature baby is pronounced ready for discharge this milestone can bring joy and relief. However, according to most parents the anxiety,

stress, and unpredictability of parenting a very premature baby does not end here. The long-awaited return home brings a shift in these worries and the frightening reality of the transfer of full responsibility for these tiny, fragile babies to their medically untrained parents (Raines, 2013).

After a long period of support from family, friends, and nursing staff during the NICU stay, normal life is expected to resume. However, not only have the parents been affected by an emotionally harrowing few weeks in the NICU, but the uncertainty of the healthy development of their baby still lies before them. Premature infants can also have underdeveloped immune systems, with even a common cold threatening readmission to hospital (Tommy's.org, 2015). In most western societies, the mother is the primary day-to-day caregiver of a new-born baby (Eisengart et al., 2003). In England, this may change in coming years with the recent legal change from maternity leave to shared parental leave. Studies show that experiencing these stressors over and above the common stressors of being a new mother, such as sleepless nights, the management of family, housekeeping and returning to work amongst other commitments, can take a toll on new mothers of very premature babies (Arzani et al., 2015).

Mothers of premature infants often experience symptoms of anxiety and depression during the first year following the birth (Parker, 2011; Meijssen et al., 2011; Manns, 2009; Gunter, 2010; Gonzales-Serrano et al., 2012). These difficulties can result in a poor mother-baby bond, and negatively affect relationships with other children and spouses (Fleury, Parpinelli & Makuch, 2014; Neri et al., 2015).

Providing appropriate help and support during these stressful times may prevent the escalation of symptoms of anxiety and depression (Bener, 2013; Landsem et al. 2014, Parker, 2011). This could alleviate the impact of a negative bonding experience between mother and baby, potentially resulting in the baby's better development, both physically and psychologically (Mertesacker, 2003; Landsem et al. 2014). A reduction in depression and anxiety has also been positively correlated with improved relationships with other children in the family, as well as increased concord between spouses (Landsem et al., 2014). The provision of support could therefore aid the improvement of family relationships as a whole and help prevent family breakdown.

Over and above the primary goal of emotional support, these extended benefits could cut service costs in the long term, suggesting that this research could be of value in terms of government funding.

There seems to be little research focused solely on the experience of parenting a very premature baby at home during the first year following hospital discharge. This seems to reflect the reality that parents are offered very little specialized support once their baby is well enough to go home. I will now critically discuss the current literature, indicating how these papers inform my research and support the need for further qualitative research in this area.

1.1 An existential perspective

As this study takes an existential perspective, relevant existential literature will also be included in this literature review. Existential literature does not deal specifically with the experience of parenting a premature baby. However, it does shine a light on a number of key themes that are relevant to this experience, and while existential literature does not focus on the specific experience of premature parenting, it does consider mothering in a broader sense. This will be addressed in the paper in a section dedicated to the existential perspective.

2. Literature review

2.1 Literature search

The following review covers the literature on this subject published within the last 10 years. My research question considers ‘how mothers of very premature babies experience mothering these infants in the first year after hospital discharge’. My review includes research studies, articles and books directly related to my research question, as well as some that provide wider knowledge of the research area. The literature search was conducted electronically using the Summon search tool and later, the

Middlesex Library Search. This tool enables searching a wide body of databases relevant to the research topic through one electronic search. These included, *inter alia*, PsycNET, PsycINFO, PsycARTICLES, EBSCOHOST, PUBMED and Science Direct. A Google Scholar search also generated new material. Date parameters were set to include papers published within the last 10 years to ensure that sources reviewed are recent and aligned with current medical developments and service provisions.

Search terms began with 'premature' and 'premature birth', yielding an enormous number of papers, many of which were not closely related to my research question; for example, some papers focused on medical, scientific, nursing and midwifery issues relating to premature birth. The search was then narrowed by using search phrases including but not limited to 'parenting a premature baby'; 'mothering a premature baby'; 'mothering a premature baby after hospital'; 'experience of premature birth'; bringing a premature baby home', 'premature babies at home' and 'post NICU'. Variations on these terms were also entered to maximise the search coverage. This search yielded around fifty papers more closely related to my research topic. I discarded several papers that focused on medical conditions of prematurity or neonatal unit policy and selected as the most relevant papers those that focused on parenting premature babies, experiences on the NICU, provision of counselling, reviews of different models of planning for transition to home, and several studies focusing on parenting premature babies at home. A general Google search also led to relevant websites containing helpful information such as recent statistics and community services. When multiple searches using varied search terms began to return the same articles I felt a saturation point had been reached.

The snowballing method was useful for accessing relevant articles from reference lists in related articles and literature reviews. Although some of these were published earlier than 10 years ago I read those that were relevant to my research topic, such as a qualitative study by Golish and Powell published in 2003, which I have included in my literature review. The searches have been periodically repeated to ensure awareness of new studies. Since the ethical approval of my proposal in 2016 several new studies have been published on this topic. This is encouraging as it indicates that there is indeed a rising interest in this area of knowledge across a variety of fields, including psychology.

While I will demonstrate my reflexive approach throughout this review and show how I was drawn to the literature I selected, I want to focus here on some key areas that I would like to highlight further. Writing this review was inevitably influenced by my own views on this phenomenon, partly because I have experienced it myself and also because I had already read widely on the topic and begun formulating my own understanding of the wider research area. I had therefore already formed certain views, such as recognising that premature birth is initially experienced as a trauma, and that the months after discharge inevitably involve challenges. Hence I had already identified certain issues, such as trauma, that I thought were important to address in this study, but at the same time I did not want to guide the research along a predetermined path, which would have detracted from its phenomenological aim. Bearing this in mind, I went ahead and researched these areas, mindful to use open search terms that were not narrowly directive, to keep the literature review balanced. For example, when looking for trauma literature I searched ‘trauma’ and ‘birth trauma’ separately, avoiding search terms like ‘the trauma of premature birth’, which would

have returned only a narrow group of studies linking premature birth with trauma, and might have omitted other studies that might be more broadly representative of the field.

I set out to be impartial but of course I was making choices throughout the process, choosing papers to include that I thought relevant or important, based on my own views and understanding. However objective a researcher wishes to be, subjectivity is unavoidable, an insight identified as early as the nineteenth century, when Friedrich Nietzsche, laying the foundations of postmodernism, wrote in *The Genealogy of Morals,* " There is only a perspective seeing, only a perspective 'knowing'; and the more affects we allow to speak about one thing, the more eyes, different eyes, we can use to observe one thing, the more complete will our 'concept' of this thing, our 'objectivity' be." To counterbalance this unavoidable subjectivity I therefore read widely, constantly reviewing my choice of papers to ensure that I was painting as broad and accurate a picture of the existing literature as possible. For example, I had not intended to focus on research on parenting during the NICU stay because my topic focused on the period after discharge; however, it became clear that these studies really encapsulated and confirmed the early trauma element. I realised that those findings contributed to the theme of my study and needed to be represented. Therefore, although I was directing the literature search, keeping my approach fluid allowed me to be led by the research and helped create a balanced review.

No studies have been found that focus specifically at the experience of mothering a clinically healthy baby born very premature (28-32 weeks gestation) within the first year after hospital discharge. Furthermore, no studies on this topic have been

conducted in the United Kingdom. There are also no current studies that have approached the issue from an existential perspective.

2.2. Overview of the current literature

I will begin by discussing the relevant literature on trauma and birth trauma which frames and contextualizes my study. I will then review studies on my topic published in the last 10 years. The literature falls into 3 main groups. Most of the existing research focuses on the experience of parenting in the NICU and highlights the trauma experienced during the NICU stay. A few studies explore the transition home and only a small number of studies focus on the period after homecoming. I will discuss the literature within this framework and consider what it has to say about the role of emotional support for parents of premature babies.

This is a relatively new phenomenon and there is therefore a dearth of literature on the subject. Hence I have made an exception by including a qualitative study by Golish and Powell published in 2003, which provides a rich account of the premature parenting experience and whose results suggest a need for emotional support for parents of premature babies. This paper is thus directly relevant to my research and indicates the need for further research in this area. I have also included a qualitative study by Lundqvist, Hellström-Westas and Hallström (2014), investigating fathers' experiences of parenting a premature baby at home; although this focuses on fathers' experiences rather than mothers' the results provide valuable insight into parenting a premature baby and are therefore relevant to my research.

Current guidelines for postnatal and neonatal services within the UK are provided by the National Institute for Health and Care Excellence (NICE), the Department of Health, the National Maternity Review and National Health Service England (NHS). These policy guidelines will also be reviewed in order to place this research within the relevant context of service provision. As this research takes an existential perspective I will also discuss existential literature on mothering as well as relevant literature by existential theorists. To support relevance to Counselling Psychology I have also included existential psychotherapy literature relevant to this topic.

2.2.1. Using trauma as a lens

Trauma is not easily defined, though of course many practitioners and researchers have attempted to do just that. It depends largely on the individual's subjective experience rather than on objective criteria. People may respond differently to similar traumatic events, with some becoming psychologically traumatised while others do not. However, the experience of trauma, whether considered great or small, can affect or change our responses from there on (Beck 2004; Sluiter 2013).

Beck (2004a, p.28) describes birth trauma as "an event occurring during the labour and delivery process that involves actual or threatened serious injury or death to the mother or her infant. The birthing woman experiences intense fear, loss of control, helplessness and horror". A woman who gives birth very prematurely experiences some or all of these elements, which according to this definition can be classified as trauma.

Different schools of thought have developed different explanations of the psychological response to trauma; for example, the medical model takes a medical diagnostic approach. The Diagnostic and Statistical Manual of Mental Disorders-5 (American Psychiatric Association (APA), 2017) identifies a cluster of symptoms experienced after a traumatic event and labels this Post Traumatic Stress Disorder (PTSD). The DSM-5 (APA, 2017) lists PTSD under the new category of 'Trauma and Stressor-Related Disorders'. The details of the criteria for this condition are beyond the scope of this research, but they are very particular and time-specific. Individuals who meet the criteria are given a medical diagnosis and offered a specific treatment protocol. Recent statistics show that 16% of women who have had premature babies are diagnosed with PTSD (Bliss, 2020). Although this is a widely used mainstream discourse, it is only one way of making sense of trauma. The present research is open and phenomenological and therefore focuses on the individual's nuanced experience of trauma rather than seeking to match details to predetermined diagnostic criteria.

Tom Greening (1997) developed the concept of 'existential shattering' to offer an understanding of trauma from an existential perspective (Hoffman & Vallejos, 2019). Hoffman and Vallejos (2019, p.1)explain that "Existential shattering is the sudden and unexpected dismantling, or shattering, of one's self-conception and worldview as a consequence of an event or process that the individual has experienced". This is also true of mothers of very premature babies who face a sudden and unexpected change to their expectations of childbirth and becoming a mother.

Using these two points of reference as a foundation it can be hypothesized that a very premature birth may affect the way a mother views every aspect of her experience in

the first year of her premature baby's life and beyond (Sluiter, 2013). Arguably, she may experience her first year of mothering through the lens of trauma. Exploring this distinct experience of becoming the mother of a very premature baby through the lens of trauma can help us elucidate these mothers' individual experiences, in turn enabling us to determine the support that should be provided in these circumstances. Acknowledgement of the traumatic experience through the appropriate professional channels could help the mother digest her experience, while assisting her in adjusting to motherhood. This in turn could help with her attachment and relationship to her baby (Beck, 2004; Beck, Driscall & Watson, 2013; Sluiter, 2013). These studies are critically discussed below.

2.2.2 Literature on mothering a premature baby

2.2.2.1. The experience of a premature birth is traumatic

Research into parents on neonatal units concurs that the preterm birth and hospitalisation of an infant causes parents high levels of stress and anxiety (Cantle, 2013; Gangi et al., 2013; Lundqvist, Hellström-Westas and Hallström, 2014; Hall et al., 2017; Ionio et al., 2017). The sea of conflicting emotions can be overwhelming and parents can find it difficult to cope (Hall et al., 2017; Lundqvist, Hellström-Westas and Hallström, 2014).

Bener (2013) studied psychological distress in postpartum mothers of preterm infants in order to pinpoint predisposing factors in mothers that could contribute to the development of psychological distress after preterm birth. In this quantitative study 2,091 Arab mothers answered questionnaires in a hospital setting. Though much of the study focused on investigating comorbid or predisposing factors to depression and

anxiety in postpartum mothers, it was found that mothers of low birthweight infants (infants weighing less than 2,500g), which typifies mothers of very premature babies, are at greater risk of depression and anxiety than mothers of full-term infants (Bener, 2013).

A more recent qualitative study by Spinelli et al. (2015) looked at the experience of the transition to motherhood within the framework of Stern's theory of transition to motherhood (Stern, 1995). Stern suggests that the process of becoming a mother transcends labour and birth and develops gradually over the first few years of the infant's life. He identifies four themes that represent mothers' concerns during this development that relate to the following: physical care and concern to keep the baby alive; emotional care and protection; the maternal support system; and the reorganisation of the mother's identity as a mother.

Spinelli et al. (2015) conducted semi-structured interviews with 30 mothers of preterm babies currently admitted to the NICU. The resulting data was analysed using Thematic Analysis and identified four themes: disconnection from the child; perception of maternal inadequacy; loss of the parental role; and temporal suspension. The authors confirmed that these themes aligned with Stern's (1995) theory of transition to motherhood.

A quantitative study by Hall et al. (2017) used latent class analysis to assess whether heightened distress levels in parents of premature babies on the NICU can lead to poor parenting. The results showed no significant positive correlation, however, or evidence of heightened distress levels in these parents. This led to recommendations

that this element must be considered, though not in isolation. A multifaceted appraisal is recommended for assessing support needs for families post discharge.

However, a different outcome emerged when Ionio et al. (2017) conducted quantitative research to investigate whether parental stress in both preterm and full-term parents influenced dyadic interactive behaviours. It was found that preterm birth could be a risk factor for the exchange of interactive parent-child behaviours.

Hagen, Iversen and Svindseth (2016) conducted qualitative research comparing differences in coping response of mothers and fathers of preterm babies on a NICU in Norway. The content of their semi-structured interviews was analysed using Phenomenological Systematic Text Condensation. The results and discussion of this study convey a rich and emotional account of the isolation and numbness experienced by both parents. The research conveys a deep sense of fear and loss of control. This rich understanding of the NICU experience strongly suggests that emotional support may be needed further down the line.

Chourasia et al. (2012) conducted a study in a tertiary teaching hospital in India, measuring the effects of counselling on stress levels of NICU parents. A sample of 100 mothers of babies on a NICU ward completed a questionnaire measuring stress levels before counselling and 48 hours after counselling. The results were then coded and analysed using SPSS. The outcomes showed a significant reduction in stress levels related to several stress variables delineated in the questionnaire, such as sights and sounds of the NICU and staff-parent communication (Chourasia et al.,

2012). This research was carried out on a NICU, however, and supports the contention that professional emotional support is both necessary and helpful to NICU mothers.

These papers provide empirical evidence of the trauma experienced during and after premature birth, and during the baby's hospitalisation. These different avenues and methods of research all point to potential outcomes in terms of parents' emotional distress and compromised parent-infant relationships. These studies therefore point to the potential importance of my research as this trauma can colour the experience of mothering these infants during the first year after hospital discharge and beyond. They are therefore important in supporting the rationale for my study.

2.2.2.2 The transition from hospital to home is challenging

Several studies have investigated parents' experiences of the transition from hospital to home life (Raines 2013; McNeil et al., 2016; Murch and Smith, 2016; Tomlin, Deloian & Wollesen, 2016; Hemati, et al. 2017 Petty et al., 2018). This area has been explored not only by mental health practitioners, but also by nursing staff and medical professionals. The medical and nursing interest in this area relates to the investigation of the appropriate type and extent of training to be given to parents in preparation for caring for their premature infant at home (Smith et al., 2013; Berman et al., 2018).

Raines (2013) carried out qualitative research with 150 mothers of premature babies on the NICU, exploring mothers' concerns about the upcoming discharge of their babies. She found that mothers felt confident in their ability to care for their babies but had concerns about being tired and their baby needing to be readmitted to hospital.

Complementing many other studies, she found that mothers were concerned about missing a deterioration in their baby's condition. This research highlights that even mothers who feel confident about caregiving have a comprehensive concern about the wellbeing of their baby after hospital discharge.

McGowan et al. (2017) conducted quantitative research to investigate whether mothers with a previous mental-health diagnosis would manifest a decreased perception of readiness for discharge than those who had no mental-health diagnosis. A questionnaire comprising 4 Likert scales was designed to evaluate the following: the mother's NICU experience; perceptions of readiness for discharge; perceptions of care on the NICU and the mother's emotional response to the baby's wellness. The questionnaire was administered to 934 mothers at the Women and Infants Hospital in Rhode Island.

Mixed statistical methods were used to interpret the variables in the study and the outcomes showed that mothers with a previous mental-health diagnosis had reported lower satisfaction with NICU care and showed a decreased perception of their readiness for discharge (McGowan et al., 2017). This study is important because if research finds that most mothers of premature babies require further and more specialised support after discharge, this support may be even more important for mothers with a mental-health diagnosis and their babies and families.

Galeano, Marín and Semenic (2017) also researched parents' experiences of preparing for discharge of their premature baby from the NICU.

A qualitative method was used in which 10 semi-structured interviews were conducted. Data was analysed using the Grounded Theory method and open and axial coding was performed. Results showed that parents felt happy and joyful that their baby's health was improving and stabilising. Parents also reported feeling frightened, mostly in relation to their baby's fragility; they anticipated with horror the possibility of dropping the baby, or being unable to care adequately for it at home. They also feared the baby becoming unwell and that they would not recognise the signs. The research also identified factors contributing to a positive discharge, such as good communication with the medical staff and training in practical caregiving skills (Galeano, Marín & Semenic, 2017).

Smith et al. (2013) present an overview of the elements they deem necessary for a successful discharge preparation programme. They highlight the importance of training and support for parents in relation to caring for their baby, understanding the baby's medical needs and what they may expect when they are back at home. The article offers a comprehensive overview of the necessary preparation (Smith et al., 2013). It is worth noting however, that this is written from the perspective of hospital staff and that the article does not take into consideration that parents may be unable for various reasons to put these principles into practice after discharge or whether some modification to them might be required.

The current research in this area provides overwhelming evidence that parenting a premature baby at home after discharge is emotionally and physically challenging (McNeil et al., 2016; Murch and Smith, 2016; Tomlin, Deloian & Wollesen, 2016; Berman et al., 2018; Petty et al., 2018). The research outcomes are unanimous in

recognising a need for the recommendation and provision of emotional support for parents of premature babies.

2.2.2.3. Support can improve the transition experience

Research has explored whether provision of support can make a difference to the experience of the transition to home. Toral-Lopez et al. (2016) researched parents' perception of needs after discharge, focussed on an early discharge programme in Grenada, Spain. The authors cite a view that early discharge from hospital followed by appropriate support at home is better for the premature baby and its mother; earlier research has shown that a protracted hospital stay may cause complications and negatively impact both preterm infants and their parents (Sadrudin et al., 2012). However, the timeframe and medical parameters cited as necessary for this early discharge programme seem similar to the standard discharge criteria in England.

Toral-Lopez et al. (2016) were concerned to investigate mothers' perceptions of what their needs would be post discharge. These mothers were contacted 1-2 weeks post discharge for a follow-up interview. The early discharge programme comprised significant training in infant care, feeding and immunisation techniques. The programme also offered home support by a nurse specially trained in the needs of premature babies. This programme therefore suggests fuller and more specialised home care after discharge. Thematic Analysis was used to analyse the results, which showed that parents valued the support of the early discharge programme. However, the authors found inadequate coordination between pre and post discharge.

Outcomes also showed that medical information about their child's condition was insufficiently explained.

Ingram et al. (2016) investigated whether family-centred neonatal discharge planning would reduce post-discharge healthcare usage. This family-centred approach aims to involve parents in the baby's care plan from the start of the NICU stay. The goal is to improve parents' understanding of their baby's medical condition and expectations of the journey ahead, and in so doing reduce parental anxiety and fear during the NICU stay and transition home. This study implemented the 'train to home' system in which parents are presented with a laminated card with a train depicting their baby's journey to discharge. This train is used to delineate the baby's progress from stage to stage, culminating in discharge to home.

The ongoing education and open communication with hospital staff aimed to prepare the parents for taking their baby home with reduced anxiety. The hope was that increased parental confidence and lower anxiety would reduce parents' resort to health services after discharge. A quasi-experimental approach was adopted, with one interview taking place pre-discharge and a second interview later. Results showed a slight decrease in the use of out-of-hours emergency care. However, this coincided with the implementation of 111 out-of-hours support, which brings into question the reliability of this study.

An intervention programme developed in Australia is called Triple P, or the Positive Parenting Programme. This multilevel support programme was developed in Queensland, Australia for parents of children considered at risk for various reasons.

The programme was adapted for parents of new-born babies (Sanders, Turner & Markie-Dadds, 2002), and has since been further adapted for parents of premature babies (Whittingham et al., 2014).

Whittingham et al. (2014) researched the effectiveness of this programme for parents of premature babies. Their unequivocal results showed that parents confirmed the need for a discharge support programme. The results also highlighted the unique experience of the premature journey; parents expressed a need for specific tailoring to the premature journey. Parents also raised the need for further information and support in relation to their baby's development and medical needs after discharge (Whittingham et al., 2014).

Evans et al. (2017) subsequently investigated the application of Baby Triple P to parenting a very premature baby. Results showed that participants found the programme helpful and felt able to apply the knowledge and skills gained in the original training throughout the first year of their baby's life.

A common focus across the literature seems to be assessment of the usefulness of nursing support at home after discharge. Results reflect that a continuity of nursing support at home would help to ease parents' transition. Studies that have implemented this support with weekly home visits or regular phone calls have witnessed a reduction in parental anxiety and increased feelings of support and confidence (Galeano, Marín & Semenic, 2017). A Swedish study trialling nursing support via a video conferencing system found that knowledge of access to support in itself reduced parents' anxiety and increased parental confidence in their ability to care for their infant. Though some

of these studies are a little older than my set parameter I feel that the value of their assessment of parents' experience of help after discharge gives these results continued relevance (Ericson et al., 2018).

Tomlin, Deloian and Wollesen (2016) provide useful guidelines on what should be taken into account when planning programmes for discharge preparation. They address both the preparation for discharge and transition issues and make recommendations for home care to assist with transition. They recommend that home-visiting staff should be trained to understand the specific medical and developmental needs of a premature baby, and assess and respond to the emotional needs of both parent and child.

An important aspect highlighted is the need to recognise the limitations of the role and to incorporate knowledge of how to refer parents to specialised professionals where needed. This supports the idea that there may be a need for specialist mental-health professionals in a home-based care plan and that specialised knowledge of the challenges of parenting a premature baby is important. (Bowles et al., 2016; Tomlin, Deloian and Wollesen, 2016).

Aloysius et al. (2018) outline recommendations for post-NICU support. They state that planning for a smooth and manageable discharge needs to begin at the start of the NICU stay and that keeping parents informed about the forthcoming transitional stages of their baby's journey will help parents feel prepared and less anxious along the way. They also suggest collaboratively planning a potential discharge date in advance so that discharge should not come as a surprise. Supporting earlier findings, they

highlight the value of continuous training and support, including life support training before discharge and breastfeeding support, together with the opportunity to room in with the baby at the hospital to practice taking care of it before discharge. Contacting the NICU by phone after discharge with any concerns or questions is also encouraged.

Aloysius et al. (2018) discuss offering a 'next steps group' designed to bridge the gap between hospital and home. Arranged by the clinical psychology team, it comprises a professionally run group of 7 sessions, covering topics relevant to a premature baby's development. It is also designed to help maintain contact with other NICU mums and NICU staff, which they believe can be supportive during this time. The authors also mention the importance of specialist neurodevelopmental follow-up after discharge, due to the high-risk status of premature babies. The importance of peer support is highlighted as an important element of the programme, as well as an important area for future development. This programme has been implemented in north-west London and has received a positive response in parent surveys (Aloysius et al., 2018).

It is evident therefore that a number of studies discuss or propose programmes that have been designed to provide this preparation and support and that most of these provisions have been created and implemented outside England (McNeil et al., 2016; Murch and Smith, 2016; Tomlin, Deloian and Wollesen, 2016; Evans et al., 2017; Ericson et al., 2018). There is a strong focus on preparation for discharge, but little practical support and availability is put in place for babies' return home. Aloysius et al. (2018) have compiled the most comprehensive support programme to date, and this is receiving positive feedback; however, this programme is only available in one area of London.

2.2.2.4. Stress and challenges continue when a premature baby comes home

Research carried out after hospital discharge shows that the emotional challenges that begin in hospital continue over the first year following discharge (Meijssen et al., 2011; Parker, 2011; Discenza, 2012; Neri et al., 2015; Granero-Molina et al., 2019). The research reviewed here shows that this stress and anxiety is linked to the fragility of the preterm infant even after discharge, and the fear of sole responsibility for the baby's care (Raines, 2013; Garfield, Lee & Kim, 2014).

A preterm baby is usually discharged from NICU when it reaches all the milestones of autonomous functioning like a full-term new-born baby. This includes unassisted breathing, eating, temperature regulation, and coordinating the process of sucking, swallowing, and breathing (Jefferies, 2014). However, although these babies are now able to function without medical assistance, it can be difficult for a parent to suddenly make the adjustment to trusting in these abilities after weeks of watching the baby's close dependence on medical interventions and machinery (Gunter, 2010).

The fears described above can lead a parent to believe that they are not capable and skilled enough to care for their baby. These parents can be described as having low parental self-efficacy. Bandura defines self-efficacy as the sense of being able to manage a task effectively and successfully (Bandura, 1982). Low parental self-efficacy has been linked to postnatal depression and has also been linked to a poor mother-child bond (Fleury, Parpinelli & Makuch, 2014).

Pennell et al. (2012), developed a new measure of parental self-efficacy and parental self-competence relevant to preterm parents, and conducted quantitative research expected to support these ideas. However, their research yielded surprising results showing that self-efficacy scores and psychological symptom scores were not overall significantly lower in parents of very preterm infants than in those of full-term infants (Pennell et al., 2012). Their sample of 155 participants did meet the criteria set by their a priori power analysis; however, their sample comprised only 155, of whom only 123 were parents of preterm infants. A larger sample might have yielded different results (Field, 2009); it is the rule that the smaller the sample size, the less reliable the results. Further research would yield a clearer picture and a stronger basis for generalisability.

2.2.2.5. Delayed resolution

Many premature babies continue to develop normally; however, it is possible that an early birth and the process of developing outside the womb can cause certain health problems and developmental abnormalities. Breathing support and certain types of medication needed for the baby's survival can sometimes affect their hearing and eyesight (Blencowe et al., 2013). Therefore, when the initial milestones are reached and a premature baby comes home, it remains unclear whether any health or developmental problems will arise. Understandably, this creates constant anxiety in parents throughout the developmental years. This is compounded by the fact that premature babies are expected to take longer to reach their milestones, which extends this stressful time period (Discenza, 2012).

González and Espitia (2014) conducted an Interpretive Phenomenological study looking at mothers' experiences of caring for a premature baby at home in the Colombian community. Their findings support Discenza's (2012) research, concluding that these mothers experience common fears about their baby's health and development post discharge. These mothers also described an oppressive sense of responsibility for caring for the child because other family members were so afraid of the babies' fragility (González and Espitia, 2014). The results indicate a need for further research in this area.

There are limitations to this study as the findings are specific to the Columbian community. Due to the difference in NICU practices, such as being allowed access to their baby for only 30 minutes a day during the NICU stay, and many differences in suggested home care, the results of this study cannot be generalised to apply to mothers in other countries. This study also fails to specify the period of time focussed on for the research, making it difficult to apply these findings more generally.

Hall et al. (2013) also investigated the experience of becoming a mother to a very premature baby. Secondary analysis was performed on data previously analysed and Hermeneutic Phenomenology was used. Van Manen's phenomenology was applied to explore this phenomenon in relation to the four existential elements of lived space, time, body and relationship. The authors looked at these areas of experience in the NICU, the transition home and experiences post discharge (Hall et al., 2013).

The wide parameters of this study included mothers of babies born between 25 and 32 weeks. The difference in medical prognosis for babies of a lower gestational age

can generate a wide gap between participants' experiences and in turn affect the ability to generalise this data. For example, survival rates at 24 weeks gestation are approximately 60%, rising to 89% at 27 weeks and 95% between 28 to 32 weeks (Tommy's.org, 2015). Tighter parameters, such as including only mothers of singleton babies born at a similar gestational age and focusing on a specific timeframe post discharge, could possibly achieve a more precise understanding of the phenomenon it aims to explore (Smith, Flowers & Larkin, 2009).

Although it falls outside my publication-date parameter, there is one study from 2003 that I found extremely insightful and worth incorporating into my literature review. Golish and Powell (2003) conducted qualitative research using a dialectical framework to examine communication between family members after a premature birth. A qualitative interpretative approach was applied and several themes were identified that reflected participants' experiences. Participants unanimously expressed an experience of ambiguous loss, torn between the positive aspects of the birth of a child and the negative aspects of the premature birth and all that comes with it.

The research highlighted how the premature parenting journey seems to continually create tension between opposing poles: life and death; joy and grief and support and loneliness. The study elegantly describes mothers' painful experiences of the loss of the fantasy of the joy of childbirth and the anger, jealousy and sadness that can ensue. Most interestingly, it focuses on the difficulty of feeling denied the right to express these feelings because they do after all have a live healthy baby (Golish and Powell, 2003).

The exploratory style of this investigation gives a taste of the richness and importance of the emotional experience of premature parenting. Although there is plenty of scientific research on this topic, as well as books guiding parents on what to expect after returning home, the raw personal experience of this journey remains mostly unexplored. This study holds that expression of this experience from a personal perspective can help us understand how to support parents through this journey and what structures need to be put in place in order to do so.

However, Golish and Powell's (2003) research does have certain limitations. Participants were interviewed using open-ended questionnaires administered via email. Face-to-face interviews could have allowed a closer, more accurate expression and observation of their experience. This study is also limited by its wide inclusion criteria, notably the inclusion of babies born between 24 and 34 weeks. As discussed in relation to Hall's research, the discrepancy between the experiences of parents of babies born at different gestational times makes generalisation of results problematic. Similarly, many participants had multiple babies, not all of which were considered clinically healthy. Nor did the researchers focus on a particular time period of parenting, such as the first year. These points add to the difficulty of generalising the authors' findings.

Most recently a qualitative study by Granero-Molina et al. (2019) examined the experience of mothering extremely preterm infants in the first 12 months after hospital discharge. A qualitative interpretative approach using Gadamer's Philosophical Hermeneutics was adopted. The study included 20 mothers of babies born earlier than 28 weeks gestation in a hospital in the south east of Spain.

Data collection involved a focus group and in-depth semi structured interviews at 12 months post discharge. The data was analysed using computer assisted qualitative data analysis. The qualitative style of the research allows insight to be gained into the mothers' personal experience. The results show that the transition home was experienced as difficult, despite happiness at leaving the hospital environment. Due to the extreme prematurity of the babies many suffered long-term difficulties or needed special medical support after discharge.

The results show that living with a child with special needs required adjustment and affected both marital and family life. Social life was also affected; participants felt lonely and removed from social life. Mothers expressed fears about their baby's development and described how much of a focus this becomes in the first year (Granero-Molina et al., 2019). Emphasis was placed on the importance of support medical, emotional and peer support. The mothers also expressed frustration at the lack of specialised resources available to them at the primary-care level. Recommendations are made for better continuity of care, communication, and emotional support (Granero-Molina et al., 2019).

This study has many similarities to my research. It also uses a phenomenological approach to examine the subjective experience of mothering a premature baby during the first year. The study is also very recent which is encouraging as it confirms that this is an area of growing research interest. However, this study focused on mothers of babies born prior to 28 weeks, a distinctly different experience from that of mothering a baby born between 28-32 weeks. Chances of complications prior to 28 weeks' gestation are far more likely and could be significantly more severe. The study also

included mothers of babies who had identified health complications at discharge, differentiating it from studies of the experience of mothering a baby that is clinically healthy at discharge.

Granero-Molina et al. (2019) conducted their study in Spain and it is important to acknowledge that cultural differences relating to birth, medical systems and parenting expectations make this study particular to its location (O'Reilly, 2014). Though my study is similar in nature it is specific to the experience of giving birth very prematurely in a hospital in England and will reflect English medical, social and cultural norms.

2.2.2.6. The role of emotional support

Parker (2011) conducted a qualitative study investigating mothers' experiences of receiving counselling or psychotherapy on the NICU. Her aim was to investigate how the service could better meet their needs. Using semi-structured interviews, she interviewed a small sample of 6 mothers of very premature babies who were still on the NICU and analysed the data using a Grounded Theory approach. The results showed that all the mothers valued the counselling offered to them and described it as helpful.

The mothers also unanimously requested counselling post discharge. One mother was offered 3 sessions back on the NICU after discharge, but felt she would have benefited from further sessions (Parker, 2011). The study also highlighted that having received counselling from a NICU family support nurse, the mothers all commented that in order for them to feel understood and supported, it was important for the therapist to have

an in-depth knowledge of the NICU experience. This is important because although many therapists will see a mother who has had a preterm birth experience, these mothers are identifying a need for a specialist counsellor who can understand and empathise with their specific journey. It is also worth noting that the post discharge counselling was offered back on the NICU which might have enhanced the mothers' anxiety. Counselling in an alternative setting might be preferable.

Beresford (2015) discusses how in the past the NHS valued the concept of continued care for the family after a baby was discharged home from the NICU. It is unclear whether she is referring only to families whose baby needs continued medical support at home or also to families with a healthy outcome baby who need emotional support. However, although this continuity of care is still seen as necessary by the NHS, it has been cut due to lack of funding (Beresford, 2015). If it is not possible to finance this service through government funding, perhaps further research in this field will not only highlight the need and value of this support, but perhaps also open up new sources of funding to support this cause.

Levick et al. (2014) reviewed a peer-support volunteer programme that has been running for 40 years at Helen DeVos Children's' Hospital in the United States. Peer support begins during the hospital stay and can continue post discharge. They looked at how the programme runs and at feedback from both recipients and volunteers. Results showed that the programme is beneficial to both recipients and volunteers and that support and healing seems to be experienced on both sides of this relationship. The review includes information on the rigorous training programme volunteers undergo before being assigned a family. The training element sets this programme

apart from some other peer-support programmes discussed in the literature. Training can ensure the optimum support for both parents and volunteers. The longevity of this initiative and the positive feedback suggests that this may be a useful model of parent support both during the hospital stay and beyond (Levick et al., 2014).

Hall et al. (2015) suggest some recommendations for a successful pee-support programme, looking at the benefits and difficulties such a programme might present. They conclude that peer support can be helpful for parents of a premature baby. Internet support can be especially helpful as it is accessible anytime and anywhere, making it easy for parents to access. Face-to-face support is regarded as beneficial, but also presents difficulties, such as parents' possible reluctance to engage and share their story in a group. The necessity of training is also considered and the importance of the vetting process for volunteers, a time-consuming but essential element of this programme (Hall et al., 2015).

The research clearly points to the need for specialist support for preterm parents, but is there any suggestion that this support would make any positive difference? Not many recent studies address this question, most likely because there are no available support programmes from which to analyse results. An older study by Forsythe and Willis (2008) reported 'consistently positive results' in terms of participant satisfaction from a California programme designed to provide continuity of support during the transition from NICU to home. More recently, Cantle (2013) discusses various positive potential outcomes that can result from continued support for parents of preterm babies and their infants. However, this study, from the perspective of a child

psychotherapist, focuses more on the child's development than the parents' experience.

The most relevant and current research on this issue was conducted by Landsem et al. (2014), who investigated the long-term effects of interventions provided for preterm parents. The results showed that an early intervention programme reduces stress in parents of preterm babies during childhood. A randomised controlled trial yielded findings showing that an early intervention programme reduced stress levels in preterm parents to the same levels as those of parents of full-term babies over the period from birth to age nine, as well as enhancing concord between parents (Landsem et al., 2014). Overall, therefore, the literature suggests that specialist support for parents of premature babies will have a positive outcome on parents' emotional wellbeing as well as on the child's development.

2.3 Cultural considerations

The studies collated in this literature review were conducted in many different countries. It is important to note that different cultures will have different approaches to giving birth and different views and expectations of mothering. A systematic review by Dennis et al. (2007) concluded that most cultures provide organised support for the mother after childbirth, involving a period of care and recovery, but that this can vary widely between cultures. For example, in Chinese culture the first 30-40 days postpartum are known as the 'sitting month' and seen as a time for convalescence and behaviour restrictions applying to diet, washing, reading, watching television and going outdoors (Liu et al., 2006). Cambodian tradition also places restrictions on new

mothers during this time but these focus on avoiding strong feelings or ‘thinking too much’ (White, 2004), while Fijian woman are warned against over-exertion, sitting up or exposing themselves to the sun in order not to cause harm to the mother or baby (Becker, 1998).

Negative consequences, ranging from wrinkled skin to illness, depression and infertility, are often attributed to disregard of these practices (Dennis et al., (2007). This may result in fear and anxiety in women who choose not to or are unable to follow these practices. Following these traditions involves reliance on family or communal support, which could depend on other factors such as proximity to family, socioeconomic and material circumstances. A woman with a baby in neonatal intensive care would be unable to follow the practices described above as she would need to take care of her infant in the hospital. Cultural pressures could therefore impact her emotional state and experience of support. This discussion also highlights the fact that the mother of a NICU baby lacks the opportunity to focus on her own physical and emotional recovery post birth, which is universally accepted as important and necessary for the mother’s health and wellbeing (Dennis et al., 2007).

The medical systems of different countries also vary and NICU provision and parents’ experiences of having a baby in NICU can therefore differ widely from country to country. The impact of cultural difference is beyond the scope of this paper, but it is important to acknowledge it. It is also important to acknowledge that this study is confined to the experience of premature birth in an English NHS hospital.

2.4 Current provision of support for premature babies in the United Kingdom

The National Institute for Health and Care Excellence (NICE) has produced guidelines for the physical and emotional care of postnatal mothers and their babies up to 8 weeks after birth (National Institute for Healthcare and Excellence (NICE), 2015). The guidelines recommend the provision of information and support regarding the health and development of the baby. The mother's health is also a priority and information on the mother's health and recovery from birth is covered in detail. The guidelines also include steps to be followed to assess mothers' mental and emotional wellbeing during this time, and also recommend that new mothers be given the opportunity to discuss their birth experience with a healthcare professional. However, it is stipulated that this should not be a formal debrief following a traumatic birth experience.

In the event of an assessment showing continued low mood or difficulty in coping, the guidelines suggest referring the mother for assessment for postnatal depression following which the provision of relevant support can be arranged. The DSM-5 classifies postnatal depression as a major depressive disorder, or bipolar disorder, with symptom onset either during pregnancy or in the first four weeks after delivery (APA, 2017). Therefore while this may be helpful for mothers seeking assistance during the first four weeks post birth, it provides little guidance or support for mothers who experience emotional difficulties later in the first year.

The NICE guidance is thorough and detailed from a physical wellbeing perspective but is perhaps lacking in the guidance for emotional support. The discussion around the

mother's mental health is narrow and points only to the possibility of postnatal depression which is limiting and ill defined. However, referral to a mental health profession is the key aspect in this case which is perhaps not stressed strongly enough. Similarly in the case of a traumatic birth no further guidance is provided as to the importance of a formal debrief for the birth trauma or what pathway should be followed for the mother to access an opportunity for a formal debrief in the appropriate support setting.

In 2017 a new set of guidelines was developed, specifically focused on the follow-up of babies and children born prior to 37 weeks ((NICE, 2017). This guidance was produced after the participants in my study had given birth and is concerned with the baby or child rather than the mother. The guidelines outline the importance of preparation and information sharing for parents in the run-up to their baby's discharge from hospital and during the transition home. Thought has clearly been put into supporting parents by equipping them with knowledge and understanding of the long-term medical consequences of early birth.

Mention is also made of the psychological impact of preterm birth on parents and carers, and the importance of providing emotional and psychological support (NICE, 2017). The guidelines link this to times when a baby is transferred between units or leading up to discharge. While the guidelines suggest extending the child's long-term follow-up to age 4, no mention is made of the long-term psychological impact on parents and carers or the need for assessment or provision of emotional support.

The guidelines seem thorough and well outlined, but their success relies on their implementation by healthcare workers on the ground, who need to be trained in the specific needs of premature babies and the related medical and psychological impact of their condition. It is important to investigate mothers' experiences of these services and whether they are experienced as supportive. The guidelines are entitled 'Postnatal care up to 8 weeks after birth', when in the case of a premature birth this would end at the time of hospital discharge. Furthermore, while the timeframe of the care of the baby may be appropriate for corrected age, the mother's physical and emotional recovery will not match this timeframe. The baby's developmental needs are well covered, but the needs of mothers perhaps require more attention.

According to guidelines for both normal and premature babies, follow-up is provided up to 8 weeks post birth. Current research shows that in many cases of both full-term and premature birth, mothers only begin to process their birth experience and develop their mothering identity later into the first year. There is no support for mothers during this time, which research shows, is a time of emotional and physical transition that can bring mothers many challenges.

Better Births (The National Maternity Review, 2017) was published by the National Maternity Review team and the NHS to provide a plan to improve maternity services across England over the following five years. The report addresses varied aspects of maternity and postnatal care. It is refreshing to see that the mental health of new mothers is prioritised. The review recognises inconsistencies with the implementation of mental-health care support relating to birth and that a high number of maternal deaths are related to mental-health difficulties. The review recommends prioritising

better access to mental-health support services for postnatal women. The setup of community maternity services hubs is proposed as a solution for quicker access to specialist care, including mental health. It is encouraging to see that a 2019 Better Births Progress Review shows that access to postnatal mental-health services has improved (NHS England, 2020).

Specialist neonatal care is considered in this plan but is focused on specialist care for mother and baby at the time of birth or during hospital stay. No mention is made of support for mothers after hospital discharge or any specialist provision for premature babies in the setup of the community hub. While the hub aims to provide quick access to specialist support for all mothers, nothing is suggested in terms of specialist training of community midwife or nursing staff in the needs of premature babies and their mothers to help them understand which services and professionals would be most appropriate. Staff training is listed as a priority but it is not clear that understanding of premature babies would be included in this training, which would be an opportunity to make a significant difference to the care provided.

Special focus is placed on neonatal services in the ‘Toolkit for High Quality Neonatal Services’ developed in 2009 (NHS, 2009). This toolkit outlines eight areas to be strengthened in neonatal care, including organisation of neonatal units, staffing of neonatal services, care of the baby and family experience, transfers, professional competence, education and training, surgical services, clinical governance and data requirements. These areas are important in terms of provision within the hospital setting but do not address the area of psychological support after discharge.

It is encouraging to see that in more recent policy plans effort has been made to address the needs of postnatal mothers' mental-health needs and that progress is being made in terms of support provision. It is also encouraging to see that that mothers and babies needing neonatal care are also being considered. However, it is clear that the emotional needs specific to the premature birth experience are still not given significant attention and that the window for assessment and care for mental health should be extended both for preterm and full-term mothers. As the report acknowledges, these changes would be subject to funding; given the financial constraints facing the NHS, some of these guidelines have not and possibly will not be implemented in the way intended; however, it is important that this remains an area of progress and development. Recent research conducted by Bliss reports that currently no nation in the UK is reaching national standards for psychological support in neonatal units. In England, 41 percent of parents had no access to a trained mental-health worker and 30 percent of parents had no psychological support at all. Closely relevant to this research, statistics also show that 45 percent of parents had no access to psychological support when they needed it after hospital discharge.

2.5 An existential perspective

While this study did not set out to be an explicitly existential study, as an existential psychotherapist my understanding of the experience of mothering a premature baby and my interpretation of the literature on this topic is influenced by my existential perspective. While reviewing the literature on this topic it became apparent that mothering a premature baby resonates with experiences that epitomise key existential concepts. Exploring this phenomenon in relation to these ideas provides a new and

interesting perspective that can help make sense of the challenges faced by these mothers.

2.5.1. Existential literature on mothering

I have found little existential literature that focuses specifically on the experience of mothering a very premature baby. However, existential literature does consider the experience of becoming a mother. The existential exploration of motherhood has been examined either from a feminist perspective, looking at the roles of mothers in society, or in terms of their meaning in relation to their experience. Simone de Beauvoir wrote about what being a mother entails and how mothering behaviour influences the mother's transition into her new role in society (de Beauvoir, 1997). De Beauvoir, Kristeva and Butterfield focus on a mother's evolving role in society and consider this from a philosophical and theoretical perspective (Kristeva, 1987; De Beauvoir; 1997; Butterfield, 2010). More recently, a Danish quantitative study looked at existential meaning among first-time full- term and preterm mothers (Prinds et al., 2014). Most recently, Claire Arnold-Baker's (2015) exploration of the transition to motherhood provides a phenomenological understanding of how new mothers experience a change on all four dimensions: physical, personal, social, and spiritual. This literature will now be discussed in more detail.

Simone de Beauvoir made significant contributions to existential philosophy and paved the way for modern feminism (Patterson, 1989). For the purposes of this paper only her work on motherhood will be explored. De Beauvoir's (1949, 1997) book 'The Second Sex' focuses on women's secondary position in society in the 1930's and 40's,

speaking out strongly in support of female emancipation and freedom of choice. She also explores motherhood through this feminist and existential lens, questioning the origins of the desire for motherhood and whether having children is an innate natural desire or simply a construct of patriarchal society. De Beauvoir's focus is on the importance of the individuality and independence of the woman and her freedom to choose or protect an identity of her own, separate from the mothering role.

In the chapter on motherhood de Beauvoir's exploration of different women's experiences of pregnancy offer an insight into the enjoyment experienced by many in the third trimester of pregnancy (pp. 618-621). This period is described as a long holiday when the mother can step back from duties and responsibilities and be completely focused on herself and her growing baby. This period is also described as an opportunity to reconcile the desire to remain one with the baby and the acceptance of the developing individual identity of the soon-to-be-born baby who will become separate from her. These explorations highlight what is missed by the mother after an early birth and the extra challenge of facing motherhood without the opportunity to benefit from this gradual transition.

De Beauvoir explores how after the birth the demands of a new baby are sudden and intense and how the new mother must process this change from her baby being part of herself to becoming an external chore and responsibility. She also reflects on the struggle of the baby being its own separate self, like a stranger whom the mother will need to get to know and learn to understand. Moreover, the new baby gives little back to the mother in these early stages; there is an element of altruism that drives the mother's care and feeling for the baby. She recognises that even when she

experiences great joy from her baby, her personal freedom is curtailed by her maternal duties. These accounts from mothers of full-term babies are important to bear in mind when exploring the experience of mothers of very premature infants as this can help identify which experiences are particular to preterm mothers and which might be shared by all new mothers. Many of these ideas will be interesting to consider in relation to the outcomes of this study.

Kristeva (1986a) criticised the first-generation feminist view that identification with both sexes was necessary to emancipate the female sex. She saw value in embracing certain aspects of femininity and recognised that maternity should be a choice for women and a question to be considered by future female generations. However, de Beauvoir had arguably created the space for these questions to be explored and challenged. Kristeva (1986a, p. 194) wrote that identity is “plural, fluid, in a certain way non-identical”, offering women the freedom to shape their own views and responses, including with regard to the question of motherhood. While suggesting that women should be free to choose or decline motherhood, Kristeva recognised that motherhood has been the “seat of social conservation” (1986a, p.237) and the role women and maternity play in the perpetuation of society.

Unlike de Beauvoir, Kristeva saw the desire for a baby as a natural instinct, a view which drew criticism from feminists (Patterson, 1989). However, she proposed that the source and goal of this desire was open to debate and interpretation for women of all generations. She refers to pregnancy as a division of the flesh - the separation from oneself to embrace life in the birth of the child. While the experience of pregnancy is described as complex and wrought with conflicting feelings of invasion and purpose,

she finds these resolved in the experience of mothering a new-born baby, which she describes as giving the mother the opportunity to experience a unique and intense love for another unequalled in any other relationship. She sees navigating the early mothering relationship as a slow, complex process of learning, and attributes a great sense of achievement to a woman's ability to form a mothering identity while maintaining her individual identity and other roles and purpose in society: "But the slow, difficult and delightful apprenticeship in attentiveness, gentleness, forgetting oneself. The ability to succeed in this path without masochism and without annihilating ones affective, intellectual and professional personality - such would seem to be the stakes to be won through guiltless maternity." (Kristeva, 1986a p. 209)

These views on the transition to motherhood for full-term mothers will also be important for preterm mothers. They will face the same existential questions and transitions as Kristeva outlines, but compounded by factors relating to prematurity. As the current literature suggests, modern western mothers are likely to be navigating a number of other social roles alongside motherhood, including professional, familial and social responsibilities. They might well also be navigating social constructs and expectations in all these realms, making the ideas presented in this literature relevant to their experiences.

More recently, Butterfield (2010) proposes that just as de Beauvoir (1997) argues that there is no such thing as the ideal feminine, there is also no such thing as an ideal mother. She argues that the 'ideal mother' will always be a relative concept, conditioned by what is deemed 'ideal' in a particular place or time. There will always be societal expectations and stereotypes but it is up to the mother to align these

against her own morals and values and navigate a path that fits with societal expectations without compromising what she feels is best for her child. This can be a challenging process and can only ensue once a set of personal values and ideals has been established. This notion can be important for mothers of premature babies as the needs of their babies may differ from the expectations and norms of others around them, and they may find it challenging to uphold what they feel is best for their baby.

Butterfield acknowledges that motherhood is an ambiguous concept. Like Kristeva, she views the mothering identity as fluid and individual: “It is up to me to choose what being a mother will mean to me, how I will respond to the prescribed social scripts, and how I will live this identity” (2010, p. 69). This acknowledgement can be liberating for a mother, particularly for the mother of a premature baby, whose feelings towards the baby and developing feelings as a mother may take a slow and unique path. This concept challenges the idea that mothers are supposed to feel and act in prescribed ways and that mothering should follow a particular format. By acknowledging that mothers tend to wear what she terms ‘the mask of motherhood’ and pretend that the mothering journey is exclusively easy and sublime, she releases mothers from the pressure of meeting this unreasonable ideal. Butterfield encourages mothers to strive for authenticity in mothering, balancing their own values with societal norms. The premature parenting journey does not follow the expected norm and these flexible attitudes to mothering offer an important and comforting perspective. These views can be helpful for women struggling with their transition into a conventional sense of motherhood and may provide them with encouragement to accept different and unique ways of being a mother.

More recent studies have analysed experiences of mothering from an existential perspective. One of these examines the experiences of mothers of premature babies. Prinds et al. (2013) surveyed studies of existential meaning-making in transition to motherhood. A scoping review was conducted of studies carried out between 1990 and 2010. Eleven papers were analysed using Emmy van Deurzen's four dimensions as a theoretical framework. In respect of the *umwelt* or physical dimension, childbirth brought an awareness of physical boundaries and limitations, but also a consciousness of one's body and the opening of possibility.

The *Mitwelt* focused on the new relationship with the baby, but also the way other relationships changed because of the baby. This raised questions of purpose and belonging. The relationship with the baby also introduced a 'fear of loss of the child and therefore a confrontation with aloneness and failure' (2013, p.17). The *Eigenwelt* brought challenges to the inner self, introducing questions on priorities, values and authenticity and the path to creating an authentic mothering identity.

In the dimension of the *Uberwelt*, a spiritual experience is attributed to birth, not necessarily from a religious perspective but arising from the awe generated by the process of birth. This, however also brought a more vivid awareness of death, which could be experience in either a positive invigorating way, or a negative fearful way. The study concludes that 'motherhood is an existentially changing event, reorganising values and what makes life worth living and raises questions about mortality and meaning of life' (2013, p.21).

Prind's (2013) study is highly relevant to this research as it too explores a number of existential themes relating to motherhood. It is also valuable as it includes several papers focussing on this phenomenon, offering a broad overview of current literature.

It will be interesting to consider the themes covered in this study in relation to the outcome of the current study.

Prinds et al. (2014) conducted further research investigating whether attitudes related to existential meaning intensify and whether they differ among mothers of full-term and preterm infants. A national cross-sectional survey was carried out in Denmark with mothers who had given birth prior to 32 weeks and double the number of mothers of full-term babies. Five core items were measured relating to meaning in life, vulnerability of life, responsibility, thoughts about life and death, and "something bigger than oneself". Results were analysed to compare mothers' attitudes towards meaning. The results showed that attitudes to meaning intensified for all mothers, with no significant difference between the full-term or preterm mothers. This disconfirmed the original hypothesis.

While the results did not meet the researchers' expected outcomes, this research yields important knowledge about the existential phenomena new mothers face in the months after birth as they grapple with navigating a new purpose in life in their new maternal role. The experience of childbirth also brings an acute awareness of their own mortality and that of the new baby for whom they are fully responsible. The fact that these attitudes intensified in all mothers shows how the experience of birth and intense feelings of care and responsibility for a baby evoke an existential awareness in the mother that filters through to all aspects of life.

Arnold-Baker (2015) explores the existential dimensions of the transition to motherhood. A phenomenological hermeneutic methodology was chosen, and Van Manen's Lived Experience method was adopted. Eight first-time mothers were

interviewed on their experience of motherhood during the first year and the data was examined for common themes. Eight themes were identified and explored from an existential perspective using Binswanger's four existential dimensions as a framework. Arnold-Baker found that "becoming a mother was a complex transition" (p.154) and that mothers experience challenges on all four dimensions. Challenges related to mothers' physical experience of the world and their changing bodies; their relationship with their baby and social interactions with others, and their views of their own identity and values. Broader existential elements were also called into question, such as meaning and responsibility in life, freedom, choice, and morality. This research shines a light on the intense existential journey a new mother embarks on in the first year of motherhood. The experiences of full-term mothers will form an important point of comparison for a study exploring the experiences of mothers of preterm babies.

2.5.2. Key existential themes

While reviewing the literature on this topic, several key existential themes came to mind. These themes relate to some of the common findings in the current literature and will perhaps be valuable for further exploration and understanding of these phenomena from an existential perspective. These themes are discussed below and an explanation is proposed as to how they connect to the literature and the current study.

2.5.2.1 Thrownness

A premature birth is sudden and unexpected. It cannot be planned for and it cannot be changed. The mother is thrown into the situation of becoming a mother with a medically fragile infant. As Heidegger (1996) points out, there is nothing we can do or change about the situations we find ourselves thrown into; however, we can choose how we respond to them and what we will create from this thrownness (Heidegger, 1996). Heidegger (1996) explores the many elements of our thrownness in the world, highlighting how we are thrown into unexpected situations in the context of existing objects and other people. In the case of premature birth, the new mother is thrown into motherhood, which is not only about her, but also about her in relation to the new human being she has created and who is fully dependent on her (Heidegger, 1996).

While her baby is the most significant other on this journey, the mother will be thrown in with many other people, such as doctors and nursing staff, family, friends and other mothers. Her new situation means that all her relationships, both new and old, will need to be navigated according to her evolving needs and perspective. She also finds herself in the new and unfamiliar environment of the NICU, where she will need to survey her new surroundings and learn about new objects and new processes, figuring out what can be useful to her and what might be a barrier on her journey. The new mother of a very premature baby will therefore experience thrownness on many different dimensions, from the random event of her early delivery to the narrowness of social conventions that she suddenly finds herself challenging. While this can prove challenging and confusing, it provides an opportunity for the development of new perspectives and greater self-awareness.

2.5.2.2 Existence preceded essence

Sartre (2003) is famed for his belief that for human beings, existence precedes essence. This opposed the main philosophical views of his time. Sartre suggests that in the first instance man simply exists, thrown into the world at birth with no particular purpose. He argues that without purpose, meaning, or direction, man would continue to be physically present; his existence therefore precedes his essence. Man's engagement with his surroundings, his response and reaction to the world around him then develops purpose and meaning, and according to Sartre, becomes his essence. Even then he deems this essence to be fluid, with the potential to change and develop in accordance with the individual's free choice and engagement with his surroundings (Sartre, 2003). A very premature birth is an unexpected and sudden event into which a new mother is thrown. Sartre's views may be useful in exploring how the new mother responds to her physical situation and her new baby and how this process will determine her development towards feeling like a mother.

2.5.2.3. The inevitable limit situations of life

The research shows high levels of stress and anxiety in parents of premature babies. Existential literature sees anxiety as symptomatic of man's realisation that he is subordinate to certain inescapable facts of life (Yalom, 1981). Jaspers (1951) connects this to his identified 'limit situations': "I must die, I must suffer, I must struggle, I am subject to chance, I involve myself inexorably in guilt." (Jaspers, 1951, pp.19-20). Yalom (1981) identifies these as the four existential givens of existence: death; freedom; isolation and meaninglessness.

Awareness of these limitations and givens reminds us of our lack of control over them and the reality of the unpredictability and fragility of life. The realisation that everything that is precious and important to us can be suddenly taken away at any moment is terrifying. For this reason man works tirelessly to arm and defend himself mentally against these givens and living to sustain the illusion that they do not exist (Van Deurzen, 2010).

Humans have an amazing ability to shift their focus onto mundane activities and goals in order to enable them to remain engaged with life and daily responsibilities. “In our day-to-day lives we often evade them, by closing our eyes and living as if they did not exist. We forget that we must die, forget our guilt, and forget that we are at the mercy of chance.” (Jaspers, 1951, p.20). The experience of giving birth to a very premature baby plunges the mother into engagement with all these phenomena in a sudden and unexpected ambush immediately after the birth. The defences that have kept her safe and provided a way to relate and cope in the world will be shattered by this new existential awareness. This becomes a challenge to comprehend and recover from, but she must also immediately begin to function as a mother and proceed to learn a whole new set of skills and a new way of being, while immersed in the reality of mortality.

2.5.2.4. Ontological anxiety

The new mother of a premature baby is faced with both ontic and ontological anxiety. She is faced with the tangible horror of her tiny, fragile, medically dependent baby, a horror which is physically and scientifically based. Yet she is also overwhelmed by the

sudden change of life as she knows it and understands how to relate to it. She is suddenly confronted with human fragility and the fragility of life as we know it. "When life is not taken for granted, existential anxiety is experienced" (Van Deurzen, 2002, p. 35). After this crude awakening one can find it difficult to adjust back into 'normal' living without contemplating one's purpose and direction life and indeed the purpose of life in general, which can end so suddenly. With heightened existential awareness the world can suddenly seem a frightening and unpredictable place, creating a generalised feeling of fear and anxiety.

2.5.2.5. Isolation

Martin Buber (2000) introduced the idea of the 'I-Thou' versus the 'I-it' relationship. The former depicts a wholly reciprocal relationship in which there is full experiencing of the other. The latter, however, is a functional relationship between subject and object, lacking mutuality. Not only is the relationship different, but the 'I' is also different in both scenarios. In the 'I-Thou' relationship the 'I' captures the essence of the interaction between the two and shapes the context of the relationship. Conversely, when engaged in an 'I-it' relationship, Buber suggests that one holds back something from oneself, considering and inspecting the object from many different perspectives, and considers its position in the greater context (Buber, 2000).

Buber's (2000) account of the 'I-It' relationship can be applied to the early stages of mothering a premature baby in the hospital setting. Research has found that mothers describe their relationship with their baby as unsatisfying and breastfeeding as a functional task rather than a mutually satisfying experience (Hall et al., 2013). There

seems to be a sense of holding back from connecting emotionally with the baby and the relationship becomes functional. It would be difficult for the 'I' in the 'I-It' relationship to begin developing an identity as a mother and thereby shape the context of the relationship if she cannot capture the essence of the relational interaction. The result is a feeling of isolation in the mother and potentially in the baby.

2.5.2.6. Paradoxical emotions

The mother of a premature baby is faced with conflicting emotions such as joy, grief, gratitude and loss. The uncertainty of her baby's survival is so salient, however, that she is impelled to bond with it, to develop love for it, care for it and dream that one day it will come home. Cooper (2003) discusses the paradoxes of human nature and the battle between recognising and accepting the finitude of life, all the while engaging in life in the face of this reality. As Cooper (2003) suggests, the outcome of this internal clash can result in fear, anxiety, and helplessness in the mother. However, Emmy Van Deurzen, (2015) observes that we are always aware of our inevitable death at some indeterminate future point, and that our challenge is to find a meaningful way to live our lives until that point (Van Deurzen and Adams, 2015).

There is joy on the long-awaited day when the baby is well enough to be discharged, but there is also anxiety and fear of what lies ahead. Cooper (2003, p. 23) argues that the anxiety comes from the drive to push against 'unmovable boundaries such as death and chance.' Knowing that we are unable to beat or control them can be frightening and overwhelming. The conflict between our knowledge of the absolute and our instinct to fight it creates feelings of anxiety, fear, and helplessness. This can

lead us to question the point of living in the face of this inevitable end. How one responds to this anxiety determines how one will move forward with their life.

2.5.2.7 Embodiment

Merleau-Ponty (2012) also believed that phenomenological understanding is closely related to the sensory experience of the world. Defying the fashion for intellectualism and empiricism that prevailed in the mid-twentieth century, he suggested that true meaning can be derived only by recognising perceptual experience. He refers to this concept of embodiment as “living communication with the world that makes it present to us as the familiar place of our life” (Merleau-Ponty, 2012 p.53). He argues that the body is a constant and permanent element giving meaning to a person’s current experiences, but also collecting and storing physical and sensory memories through life that will affect all future experiences. He viewed the experience of being in one’s own body, and the experience of the body in space as central to how we relate to and progress in the world, referring to this as ‘being toward the world’ (Merleau-Ponty, 2012).

Although his writings on this area are extensive, for the purposes of this research I will refer only to these points and how they may relate to this research. The birth of a very premature baby is an intense physical experience. The sensory and physiological process of the birth and the separation of mother and baby will be central to the mother’s experience of the whole phenomenon. According to Merleau-Ponty (2012) the body will retain a memory of this experience which can affect the mother’s experience of the world and perhaps her relationship with her baby moving forward.

This is therefore a potentially fruitful avenue for exploring the experience of mothering a very premature baby in the first year after hospital discharge.

2.6. Existential psychotherapy literature

Existential therapy can be a useful therapeutic support for mothers of very premature babies. An overview of relevant existential psychotherapy literature is therefore set out below to support this proposal.

The premature birth of a baby and the neonatal parenting experience remove a parent from the world they know and understand. Existential therapy can be important at the point of homecoming, when help may be needed in re-engaging with the world in new ways. The focus would be on acknowledgement of the limitations and unavoidable eventualities we face in life and how one can respond to these limitations and create meaning and purpose in our lives alongside them (Van Deurzen and Adams, 2015; May, 1950; Yalom, 1981; Tillich, 1952). Existential therapy can help a client explore conflicting emotions and make sense of their feelings and experiences (Van Deurzen, 2010).

With a focus on the four existential dimensions, existential therapy goes beyond the inner world of the client and helps them address their challenges within the context of their personal, physical, social, and spiritual world (Van Deurzen, 2010). For a new mother, navigating the development of her own identity, her role as mother to her new baby, perhaps her role as a wife or partner, and her other roles in society, this multidimensional approach can provide a good base of support and exploration.

Existential therapy would acknowledge and validate the unique experience of the mother and address the sense of isolation that often accompanies this specific and uncommon experience (Van Deurzen, 2010).

In addition to all this, the mother has also just given birth, in itself a significant physical and emotional life event. In the case of a premature birth the body has not performed its function as expected and there may be feelings of guilt or failure (Golish and Powell, 2003). The focus on embodied experience offered by existential therapy can address the connecting of emotions to the physical experience of an early birth and living in a body that has let the mother down (Merleau-Ponty, 2012; Spinelli, 2015; Van Deurzen, 2010).

2.7. Conclusions

This literature review prompts some important conclusions. Statistics show a continuous rise in the incidence of preterm birth across the world, as well as a rise in the long-term survival rates of very premature infants. Research shows that the trauma of a premature birth results in acute stress, anxiety and depression in the parents. There is also evidence that if left unaddressed these emotional challenges can affect the mother-infant relationship. Studies have shown that premature parents feel they would benefit from emotional and practical support, and that providing this support has successfully reduced symptoms of stress, anxiety and depression. An extensive body of evidence shows that a reduction in these symptoms is positively correlated to an improvement in mother-infant bonding and relationships. These positive results are in

turn related to a reduction in rehospitalisation after initial discharge and better physical and emotional development of the infant.

Although there is much qualitative and quantitative research on this topic, a clear gap in the literature can be identified. The experience of mothering a clinically healthy very premature infant at home after discharge from NICU has received little attention and investigation. This is a time of limbo between having a clinically sick infant and the reassurance of seeing a fully developed, healthy toddler. It is also a period immediately following a traumatic experience. Research confirms that this time is wrought with fear, anxiety, and post-traumatic stress for these mothers. It is therefore reasonable to suggest that this is a time when emotional support should be put in place. It is equally reasonable to propose that the optimum support for this purpose should be provided by professionals with expertise in this experience.

Existential principles are relevant to the challenges outlined in the research discussed above and existential therapy could be useful in addressing the challenges faced at home after discharge by parents of premature infants. There is no current widely accessible provision of specialist therapy or support for mothers of preterm infants after NICU discharge. A better understanding of these mothers' experiences is important for an understanding of what support would be helpful and relevant.

3. Methodology

My research question, ‘how mothers of very premature babies experience mothering these infants in the first year after hospital discharge’ is concerned with how mothers of very premature babies (born between 28 and 32 weeks gestation) experience mothering their babies within their first year after hospital discharge. Through my research I aim to gain a rich personal account of how these women lived this experience and what it meant for each of them. This research question therefore invites a qualitative approach, and more specifically, phenomenological research, since phenomenology is concerned with lived experience and the individual’s way of making these experiences meaningful (Reid, Flowers and Larkin, 2005).

Although I had initially set out with a completely open phenomenological research question as outlined above, I was strongly advised by the Programme Approval Panel to frame my research through the lens of trauma. I was concerned about my phenomenological study being influence by a preconceived framework; however, after careful consideration I was satisfied that this approach was actually strongly supported by the existing literature, which unanimously identifies the experience of very premature birth as a trauma. Using trauma as a lens was really acknowledging the initial trauma experience and my research remains a phenomenological exploration of whether the experience of mothering in the first year is affected by this initial trauma. As an existential psychotherapist my work is shaped by the existential phenomenological approach and the value of understanding the unique experience of the individual.

3.1 Introduction to phenomenology and its existential origins

Phenomenology has its roots in existential philosophy, originating with Edmund Husserl. Husserl (1971) was concerned with the thorough examination of human experience. He was one of the first to relate this activity to science (Spinelli, 2005) and to suggest that all scientific research can only be secondary to the fundamental need to understand the essence of experience. His focus on personal introspective analysis helps us understand and make sense of existence. His reductionist approach strips back the subjective layers of a phenomenon to reveal the essence of experience. Husserl introduced the idea of bracketing, suggesting that one must put aside, but not dismiss' one's preconceptions when analysing a particular experience (Husserl 1971, 1982).

Martin Heidegger worked closely under Husserl but went on to introduce a fresh interpretation of phenomenology. Heidegger's main interest was in what it means to be 'in the world' (Heidegger, 1996). Heidegger considers man's experiences in relation to the pre-existing world around him and how he relates to this environment. He suggests that man is 'thrown into' the world and into various situations throughout a lifetime, and that man's existence is always in relation to this world and his environment (Heidegger, 1996). Like Husserl, an important element of Heidegger's work is the analyst's reflective abilities and how understanding these reflections can create an understanding of another's experiences (Smith, Flowers & Larkin, 2009).

Sartre argued that there are different ways of existing in the world. He introduced a social element suggesting that how our relationships to and with others in the world can also have an effect on the meaning we create in our experiences (Sartre, 2003). He places great emphasis on the importance of freedom, choice and responsibility

and suggests that how we engage with these elements influences our meaning making and engagement in the world (Sartre, 2003). Sartre's view suggests that the way the researcher experiences the participant and the interaction in the research interview can influence the meaning elicited from the data. This supports Husserl's emphasis on the importance of the researcher's self-reflection and the need for bracketing to introduce awareness of the process of meaning making.

Merleau-Ponty argues that although we can empathise with what another has been through, we can never truly understand it as if we had been through it ourselves (Merleau-Ponty, 2012). This is important for phenomenological research as it supports the need for the researcher to bracket assumptions and keep the analysis embedded within the text of the participants' transcripts. This idea also highlights the importance of phenomenological research as a resource for practitioners to gain a close understanding of existential phenomena that are likely to be brought into the therapy room.

It is therefore already evident how my choice of methodology was influenced by my personal interests, research aims and assumptions. As philosopher David Abram (1996) comments, "The scientist does not randomly choose a specific discipline or specialty, but is drawn to a particular field by a complex of subjective experiences and encounters, many of which unfold far from the laboratory and its rarefied atmosphere" (p. 33). After closely comparing a number of qualitative methodologies I carefully considered my ontological and epistemological position. I also considered what I wanted my research to achieve, as well as what I would like it to contribute to the field of psychology. Bearing these points in mind I concluded that Interpretative

Phenomenological Analysis was the methodology best suited to my research project (Guba, 1990; Morgan, 2007; Reid, Flowers & Larkin, 2005; Smith, Flowers & Larkin, 2009; Willig, 2008).

IPA pays close attention the subjective experiences of a particular chosen phenomenon. The researcher in IPA engages closely with the content of the participant's account, working to strip away subjective layers and connect with the essence of the participant's experience. The researcher's preconceived ideas and assumptions are bracketed, but not ignored, and are examined in a way conducing to a better understanding of the analytical process and thereby a closer understanding of the data.

Attention is paid to the inter-relational aspects of the research process, encouraging awareness of how these aspects may affect the research process and data analysis. Respect is given to participants' experience by acknowledging that although the researcher can empathise, potentially very closely, with their experience, they can never experience it in the same way as the participant. It is also recognised that the research findings will be shaped by the researcher's views, interpretation, and formulation of ideas. I will now expand on how these this theoretical framework fits with my research position.

3.2 Rationale for choosing IPA

As a counselling psychology student embarking on a qualitative psychology research project, I am choosing to work within a metaphysical paradigm made up of my epistemological, ontological and methodological viewpoints (Morgan, 2007). Together,

these views make up the basic set of beliefs or interpretative framework that guides my research process and therefore justifies my choice of research method (Guba, 1990). Exploration of my ontological and epistemological standpoint below will explain the process by which I chose my research method.

3.2.1. Ontology

My research question looks at the experience of mothering a very premature baby. This question refers to the physical, empirical reality of the birth of premature baby. However, I make the assumption that the way this event is experienced by a mother will be unique and dependent on each mother's interpretation of the event. This indicates a subtle realist ontology, which suggests that the external event of very premature birth exists, but can be understood only through human experience and interpretation, and socially constructed meanings (Blaike, 2007).

3.2.2. Epistemology

This research question aims to gain an understanding of how mothering a very premature baby at home is experienced. An assumption is made that it is possible to know how mothers experience mothering in the first year of life and that it is possible to investigate this phenomenon by asking these mothers to describe their personal account of these experiences (Willig, 2008). This research question therefore invites a critical realist approach which suggests that interviewing these mothers can give us a rich understanding of their individual experience, rather than attempting to record an objectively exact reality (Willig, 2008).

The research question suggests that the researcher can best understand this phenomenon by hearing participants' point of view and how they make sense of their experiences. This suggests a phenomenological epistemology as the phenomenological approach is concerned with what is it like for people to experience life events (Willig, 2008). The nature of this type of phenomenological research introduces the role of the researcher and their interpretation of participants' accounts. It therefore also suggests operating from an interpretivist approach (Ormston et al., 2014). This in turn introduces hermeneutics into the epistemological framework, as the role of the hermeneutic circle in the interpretation of data plays a part in producing rich outcomes that remain grounded in the data (Smith, 1983). All these elements are incorporated in the IPA method and therefore led me to this choice.

3.2.3. The suitability of IPA for this study

The ontological and epistemological standpoint of IPA is best conveyed through its three philosophical underpinnings: phenomenology, hermeneutics, and ideography. I will now explain this approach in detail and draw links between what IPA offers as a research method, the requirements of my research question, and my ontological and epistemological standpoint as outlined above (Willig, 2008).

As mentioned above, phenomenology is concerned with lived experience and the individual's way of making these experiences meaningful (Reid, Flowers and Larkin, 2005). My research question, 'how do mothers of very premature babies (born between 28 and 32 weeks gestation) experience mothering these infants within their first year after hospital discharge?' is considered from a phenomenological standpoint.

I am investigating the phenomenon of mothering a very premature baby, how mothers make sense of this experience, and what this experience means to them. The theoretical underpinnings of IPA lie in phenomenology and are closely linked to Husserl's idea of a philosophical science of consciousness (Smith, Flowers & Larkin, 2009). This theoretical basis relates to the nature of my investigation and the type of outcomes I hope to reach.

3.2.3.1. Hermeneutics

My role is that of researcher, interpreter, and analyst. The act of interpreting has brought a new dimension to the research, in that my results reflect my experience of understanding my participants' experience. IPA's second theoretical link is hermeneutics, which means that it emphasises interpretation and how the researcher facilitates the generation of knowledge through interpretation. IPA also takes into account the element of a double hermeneutic. This has made me aware of how both the way participants describe their experiences and the way I interpret this information affects my understanding and analysis of the material. Awareness of this process has helped to keep my analysis as close to the true experience as possible (Smith, Flowers & Larkin, 2009). With its roots in phenomenology and hermeneutics, IPA offers an interpretive approach to research and falls within an interpretivist research paradigm.

3.2.3.2. Ideography

Ideography ascribes importance to the unique details of particulars (Smith, Flowers & Larkin, 2009). The focus of this study is on the unique individual experience of

mothering a premature baby and it is only through a deeper understanding of the individual account that we can gain a window into what this experience might be like for a mother. IPA's analytic procedures ensure that researcher and analysis remain connected to participants' individual accounts, by basing the analysis within the text, even when writing up more subjective statements from the results. This further confirms the suitability of IPA for this study.

3.2.3.3. Research process

The data collection technique recommended for IPA is relevant to my subject topic. I think the best way to find out about the personal experience of mothering a very premature infant is through in-depth interviews with these mothers (Smith, Flowers & Larkin, 2009). IPA prescribes working with a small homogenous sample of 8 to 10 participants, a relevant and manageable target for my research (Reid, Flowers and Larkin, 2005).

3.2.3.4. Data analysis

The data analysis method of IPA involves reading and rereading participants' interview transcripts. The researcher's role is to connect with the text in an open and curious way and collect common themes and ideas that emerge from the text. This enables the researcher to gain a rich understanding of the individual experience (Reid, Flowers and Larkin, 2005). This process can achieve my intended outcomes.

There are subtle differences between the IPA coding process and other methods. These include the first stage of initial note-taking, which I see as a good way of familiarising oneself with the data before diving into creating themes. This also enables the researcher to keep a broad view of the data, without foreclosing on initial thoughts and ideas that could skew the interpretation and analysis. I also see value in completing the coding process for each individual piece of data before moving on to the next. I believe this allows the individual experience to be protected and to remain rich and unique throughout the process (Smith, Flowers & Larkin, 2009).

3.3 Limitations of IPA

Like any research method IPA has limitations. It has been criticized for being an ambiguous method lacking in clear structure. However, recent theorists such as Giorgi and Giorgi (2008) and Smith et al. (2009) have striven to clarify a structure and highlight its theoretical underpinnings to offer greater transparency and ease of use. There is further debate among IPA theorists themselves, with Giorgi and Giorgi (2000) objecting to setting a formal structure to the method. Tuffour (2017) outlines four major points of criticism of IPA which I explore below.

IPA is said to be limited by its reliance on language (Willig, 2008). The method of analysing participants' verbal accounts of their subjective experience depends on a high level of verbal ability. Willig (2008) argues that communicating thoughts and feelings in intricate detail can be extremely challenging, particularly about sensitive experiences. All my participants had high verbal ability and were able to express their experiences vividly. I can only speculate what it might be like to interview someone

who struggles to express themselves verbally and how this might in turn make it challenging to analyse and accurately interpret their data.

Jaeger and Rosnow (1988) suggest that language is restrictive by nature and can limit accurate expression. However, it can be argued that in IPA meaning is made within the context of narratives, interaction and conversation and Smith et al. (2009) argues that “our interpretations of experience are always shaped, limited and enabled by, language” (p. 194). My participants shared that they struggled in some instances to find the right words to accurately express their feelings, but overall, they found that through telling their story they felt heard and understood. In practice, of course, despite the limitations of language, we have no other means of accessing the thoughts and feelings of others.

There is also the question of whether IPA results in accurate depictions of experience or simply verbal and social constructions of events but Smith and Osborn (2008) argue that verbal accounts of people’s experiences are directly related to their thoughts and feelings. There is further concern that between the limitations of participants’ expression and the researcher’s ability for philosophical interpretation, accuracy could be lost in the nuances so crucial to subjective experience. This raises the further philosophical issue of what exactly we mean by ‘accuracy’ – faithfulness to the participant’s lived experience or objective, empirical fact? As the researcher I feel that I was certainly able to interpret my participants’ stories with a high level of accuracy, but this did involve intensive focus on understanding the participants and their data, as well as a heightened awareness of my own opinions and feelings to ensure accurate analysis. Having been through this labour-intensive process I can appreciate

how this intellectual understanding and dedication to the process is essential for accurate data interpretation. IPA's focus on keeping analysis grounded in the text and the importance of reflexivity and the double hermeneutic help to support the production of an accurate interpretation (Smith, Flowers & Larkin, 2009).

A third limitation is that IPA is concerned with individual perceptions and their exploration and understanding but does not endeavour to explain why experiences take place. Critics claim that this ignores historical and socio-cultural influences. However, Smith (2009) argues that the hermeneutic, ideographic and contextual principles of IPA ensure that these elements are acknowledged within the analytic process.

The fourth and final criticism highlighted is the role of cognition in IPA. It is questioned whether this is correctly understood and appropriately applied in IPA and some say that cognition does not fit with certain aspects of the method. The intricacies of cognition and principles of cognitive psychology are beyond the scope of this paper but Smith provides a strong argument that meaning-making, interpretation and reflection cannot be considered as separate from cognition (Smith, flowers & Larkin, 2009).

Pringle et al. (2011) discuss concerns about validity and rigour in IPA. They consider how analysis will only provide an individual and subjective interpretation of the data and that this could restrict its validity and generalisability to a wider population. However, the aim of IPA is not to provide a singular overarching truth, but an honest and accurate representation of an experience. As Smith (2009) explains, the aim is to

‘ensure that the account produced is a credible one, not the only credible one’. While this research does not aim to generalise, it does offer insight into how trauma, in particular trauma post birth, is experienced; my hope is that this research can be applied not only to other mothers of very premature babies, but to a range of situations including mothers of full-term babies. It is nevertheless important to ensure that analysis remains as rooted in the participants’ experience as possible and that the checks and balances that have been devised can ensure enhanced validity and rigour throughout the research process. Following Yardley’s four principles of validity, for example, offers this assurance and provides a clear and transparent account of the research process.

In my experience as a researcher conducting IPA, the suggested framework offers a clear and supportive structure to engage with participants’ subjective experience. Following the guidelines for good research creates the opportunity to fully embrace participants’ accounts through careful attention to their personal presentation, their speech, body language and personality. When a researcher is sensitive to context and respects participants’ individuality, this presents a rare window into raw personal experience. Although the element of creativity has been criticised for its lack of structure, it can generate rich analysis by researchers who are committed to spotlighting the subjective experience.

3.4. Other methods considered

3.4.1 Grounded Theory

“The grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon.” (Strauss and Corbin, 1990). It involves the formulation of hypotheses based on the conceptualisation of ideas found within data. There is no hypothesis to begin with and no prior reading takes place. This allows everything to emerge from the data, allowing the theory to be ‘grounded’ in the data. The aim of this approach is to identify participants’ main concern and how they try to resolve it. The main questions asked by the researcher are: What is going on? What is the participant’s main problem? How are they trying to resolve it? (Glaser, 1992).

When I considered my research question from the perspective of Grounded Theory, the three main questions outlined in the aim above seemed to set out a suitable structure for my investigation. My research question is broad in terms of each mother’s personal experience. Investigating participants’ main problem within their experience and considering how they try to resolve it might help me understand their individual experiences more profoundly, and identify the core facets of the difficulty of the experience. This focus might also be useful with regard to practical application in the wider field of psychology when my research is complete.

Although there is a clear methodological outline, the 8 stages of the process are not chronological (Glaser, 1998). The research process is circular due to the comparative analysis being constant and repetitive. This means that the researcher will move back

and forth between data and analysis as well as between stages of the process. The researcher begins by creating codes from the data which will build into higher codes, or categories. These categories will eventually grow a core category which highlights ‘the main problem’. Selective coding then begins, drawing connections between other categories and the ‘core category’. Writing memos throughout this process allows the researcher to keep track of connections and comparisons along the way (Strauss and Corbin, 1990).

There are certainly advantages to this process. The inclusion of inductive as well as deductive thinking encourages a deep understanding of the material and links between common codes and categories. Constant analysis and reanalysis of the data is a good way to process the material so that important themes emerge, culminating in the emergence of the ‘main concern’ and suggesting how that concern can be resolved or processed (Strauss and Corbin, 1990).

Qualitative research usually takes the individual as the unit of analysis, while here the incident is the unit of analysis (Creswell, 2009). This idea appealed to me in terms of the future practical application of this research. This concept implies that the emotional experiences documented are strongly linked to the incident itself. This might imply that results can be more widely applied to the general public. However, I do not see how it would be possible to say that one has investigated an incident and not the person experiencing it.

According to Creswell (2009), grounded theory is “a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or

interaction grounded in the views of participants in a study." The aim of my research is not to develop a theory, but rather to gain an in-depth phenomenological understanding of an experience. Moreover, from a personal reflexive perspective, when I take my personal characteristics into account, I do not feel that this methodology would suit my style of working. My mind is compartmentalised and when I approach a task, I need to break it down into categories and systematically plan how I am going to tackle and complete each part. I then consider and prepare how I am going to synthesise the chunks and work towards a final goal. I know that when I am unable to do this, I feel overwhelmed and become anxious about failing or being unable to complete the task. I fear that the circular process and lack of containment of this method would be anxiety-provoking for me and would not be a forum in which I could draw on my strongest points.

3.4.2 Heuristic inquiry

Heuristic inquiry would have been a suitable option for this research study as it is also an exploratory and emergent research method. It focuses on the 'what' and the 'how' of the topic under investigation (Creswell, 2009; Finlay, 2011) and the role of the researcher is recognised and considered as the main tool of data-collection and interpretation (Moustakas, 1990; Cresswell, 2013). It is a phenomenological approach that considers perception as a primary source of knowledge and proposes that this allows for a deep and rich understanding of human experience (Cresswell, 2013). It therefore also matches the aims of my research and my research position. Moreover, this method was inspired by several existential theories that would link well with the existential perspective of this study (Sultan, 2018).

While IPA has a strong focus on reflexivity, Heuristic inquiry places greater emphasis on the shared encounter between researcher and participant, involving intense interaction, self-disclosure and creating meaning from this shared experience (Finlay, 2011). This intense collaboration can have a transformational effect on the researcher and lead to creative and innovative understandings of human experience (Douglas and Moustakas, 1985).

As I have personal experience of mothering a baby born at 29 weeks and an interest in how others experienced this journey, Heuristic inquiry would have presented a good opportunity to create meaning and understanding from this experience with participants who have shared a similar experience and I therefore seriously considered this method. However, my personal experience of premature birth followed the loss of my first baby shortly after she was born at 23 weeks. Further, a few days before my daughter was born at 29 weeks, my father was diagnosed with terminal cancer and given 6 weeks to live. My experience of very premature birth was therefore a complex trauma compounded by the prior loss of a premature baby and other significant life-changing events occurring in close proximity. I felt that this would set my experience apart from that of my research participants and interfere with the collaborative process that Heuristic inquiry provides. Moreover, because of my complex experience, my interest was in how others experienced this journey and how much of my experience was related to external traumatic events. IPA accounts for the role of the researcher and the focus on reflexivity allows for the process of interpretation to enrich the research while also bracketing personal assumptions. It therefore provided a more suitable framework for my enquiry (Smith, Flowers & Larkin, 2009).

3.5 Conclusion

In IPA, an analysis is considered good when it balances phenomenological description with insightful interpretation, and when the interpretations are grounded within participants' accounts (Smith, Flowers & Larkin, 2009). The idiographic focus helps maintain the personal variations of the data as research in and of itself, rather than its value as a generalizable phenomenon. These core aspects of IPA analysis perfectly relate to the questions I have generated when thinking about what I want my research to achieve and what I want my role to be.

In conclusion, I felt that the IPA methodology would give me the best framework to approach my research and would aid me in achieving my research goals and outcomes. The philosophical, ontological, and epistemological standpoints of IPA match those of my research question and therefore helped me generate the kind of knowledge that I hoped to acquire and share with the field of counselling psychology.

4. Method

4.1 Design

This study investigated the research question: ‘How do mothers of very premature babies (born between 28 and 32 weeks’ gestation) experience mothering these infants within their first year after hospital discharge?’ The aim of the research was to explore how mothers experience this phenomenon in their own unique way. The purpose of the research was to gain a rich understanding of this experience and the needs that mothers might have during this time. In order to investigate this question, the Interpretative Phenomenological Analysis research method was adopted.

4.2 Participants

Participants included 8 mothers from south-east England, all of whom had given birth prematurely within the last 3-5 years. The mothers came from a range of backgrounds: 4 White British; 2 British Other; and 2 White non-British living in England. One mother shared that she is Jewish; the other seven did not disclose a religious identity. Seven participants were first-time mothers and one had one older child. Seven mothers were in long-term partnerships at the time of birth and one was a single parent. Mother’s age was not specified in the inclusion criteria and the mothers’ ages at the time of interview ranged from 25 to 44. The babies were all born in English hospitals between 28 and 32 weeks’ gestation, classifying them as ‘very premature’ (WHO, 2018). The babies were all considered clinically healthy at the time of discharge. I am mindful of the fact that giving birth between 28 and 32 weeks is already a publicly identifying

feature and I am therefore limiting background information about my participants to protect their anonymity.

4.3 Analytic procedure

In order to select my sample, I reached out to mothers of children born between 28 and 32 weeks' gestation and who were considered clinically healthy at the time of discharge from hospital. Only mothers of children aged between 3 and 5 at the time of interview were included. This age bracket was chosen for ethical reasons to ensure that participants who had found this experience traumatic were unlikely to be in in the midst of their trauma as a significant amount of time had passed since their experience. The upper limit of age 5 was chosen to ensure that not too much time had passed, so that the experience was still fresh in participants' memories. Another reason for this upper limit was that medicine and science progress at such a rapid rate that the experience of 10 years ago is likely to be significantly different from an experience 5 years ago. These tight parameters have added to the richness of my interview material and have also created a basis for close comparison between cases (Smith, Flowers & Larkin, 2009).

From the beginning, I was intent on maintaining tight participant parameters to enhance the significance of my research. However, this made recruiting participants challenging and time-consuming. At times I regretted this choice but ultimately, I feel that a sample group with limited variables has strengthened the understanding of the individual accounts and made this research richer and more significant. A larger number of variables would have made comparison more difficult and less reliable.

A decision was taken not to exclude mothers who had been diagnosed with Post Traumatic Stress Disorder or other mental- health diagnoses following their premature birth experience. The rationale for this was that excluding this group might have excluded important accounts of the experience and its emotional ramifications, potentially reducing the significance of the results. This was balanced by the sensitively considered length of time since birth discussed above, ensuring a low risk of participants being harmed by this research. I did not specify parameters for the age of the mother as I wanted to maximise my opportunity to recruit a sufficient number of participants. However, due to ethical considerations, I did not include mothers who were pregnant or who were actively trying to conceive at the time of the interview.

4.3.1 Recruitment process

In order to recruit participants I contacted Bliss, an organisation that provides various types of support for parents of premature or sick babies. The Research Engagement Officer showed interest in my research and after completing the necessary paperwork Bliss agreed to support me in the recruitment of my participants. They provided me with a letter of confirmation of support. I had originally planned to contact other organisations for support as well, but the strong response I received through Bliss made this unnecessary.

I also spoke about my research at a Bliss tea party for parents of premature babies from a particular hospital NICU, held to mark National Prematurity Week. Although interest in the research was generated, the children were not yet old enough to meet the ethical requirements.

After the research proposal was publicised by Bliss, a large number of emails were received in the dedicated email account advertised on the flyer. The mothers who contacted me were eager to participate and showed appreciation for my efforts to explore this topic. This response was very encouraging, and highlighted the importance of this research. The overwhelming response made me realise that participants were not simply doing me a favour by participating, but that they too saw value in this research. Seeing how others wanted their story to be heard changed my perspective on the research, highlighting how this process aimed not just to achieve a personal goal, but to give others a voice and acknowledgement.

Unfortunately, not all applicants met the research criteria and in these cases I emailed them back a personalised email thanking them for their interest in taking part in my research. I explained that my study was bounded by different parameters that had to remain narrow and specific and that I was sorry I would not get a chance to hear their story. I also added that their interest in participating was encouraging and I thanked them for that.

I had to request that Bliss send out the advert two more times before I was able to recruit 8 participants who exactly fit the criteria. Potential participants were emailed a participant information sheet and encouraged to read through the paperwork and confirm whether they would still be happy to participate. I also encouraged them to share any questions or concerns they might have. Once they were ready to go ahead, I booked a confidential meeting room that would be local and convenient for them. I ensured that the interview locations were suitable for a confidential conversation, but

also had a professional reception to ensure the safety of both researcher and participant.

4.3.2. Interview process

Semi-structured interviews of between 50-60 minutes in length were conducted with a sample of 8 participants. This time frame provided sufficient scope for participants to describe their unique experience, but was short enough to allow them to feel focused and contained (Smith, Flowers & Larkin, 2009). The interviews took place in a small board room in a large office space in central London, a meeting room in a public library and a counselling room at a therapy clinic. Although compensation for travel expenses and childcare costs were offered, participants declined to take up these offers. At the start of each meeting a review of the paperwork was conducted. All participants were happy to sign the informed consent forms when invited to do so. With their consent, all interviews were recorded using a voice recorder.

4.3.3. Interview schedule

I asked my participants 8-10 open-ended questions. My interview schedule appears below:

1. What were the initial days and weeks like after you brought your baby home from hospital?
2. How did you experience the next few months as your baby grew and developed during the first year after hospital discharge?
3. How did your experience affect your feelings of being a mother?

4. What was your experience of bonding with your baby?
5. How much support would you say you had during this time?
6. What did you find easy?
7. What did you find difficult?
8. How did you experience your baby's milestones?
9. I noticed you mentioned experiencing conflicting emotions; could you tell me more about how you made sense of that?
10. Is there anything that you feel could have made a positive difference to you during that time?

As the aim of this research was to gain a phenomenological understanding of the experience of mothering a very premature baby after hospital discharge, I chose to start with a very open first question to avoid setting a preconceived framework for the interview, and invited participants to share their subjective experiences over that time period. I also included some questions on elements that had been highlighted in previous literature as posing a potential challenge for new mothers of premature babies, such as bonding and developing an identity as a mother. I was mindful to keep these questions open to ensure that they would open up a discussion of the phenomenon without leading participants in any particular direction.

I also included the question 'what did you find easy?' to open up an opportunity for a balanced account of the experience. However, I ended up questioning this decision as some participants seemed surprised and almost annoyed to be asked this question about what had been such a difficult and stressful time. This response caused me to feel uncomfortable and perhaps even guilty for seeming to imply that some of their

journey might have been easy and I worried that I had perhaps offended them. I took time to examine this interaction and the strong feelings it brought up for participants and for myself. This interaction highlighted participants' struggle to feel understood, and added value and depth to my analysis.

I included a question about conflicting emotions as I anticipated that this was likely to come up in the interviews. However, I only asked this question where it was relevant to what the participant had shared. I also included a question about participants' experience of support and what they thought could have been helpful, as the information generated might add to the potential impact and importance of this study.

No two interview questionnaires were identical. In some cases, the material overlapped, and I adapted the questions accordingly. The semi-structured format allowed me to contain the conversation within the boundaries of the interview topic, but also allowed participants to speak freely and share genuine memories and feelings without restriction.

Many elements of my participants' experience resonated with me and what I had gone through with my daughter. I found it challenging having to withhold my own similar experience until after the interview. My instinct was to share and compare stories, but I could see in the moment how this would have detracted from the focus on participants' accounts and changed the rapport in the interview. I was therefore pleased that I had chosen to reveal my experience only afterwards, as I believe it would have been impossible for participants to speak openly without wondering about my experience or perhaps my judgements on what they were saying.

At the end of the interviews I greatly enjoyed the opportunity to disclose that I had had a similar experience, and to share that some of the points raised resonated with me. I felt rather nervous at being open for questioning but these conversations proved light and collaborative, and I feel they contributed importantly to balancing the power in the room. Being with women who had gone through an experience similar to my own gave me a taste of peer support, something that, unlike my participants, I had never been offered. I enjoyed the interview process and felt tremendously grateful to my participants for sharing their stories with me.

4.3.4. Debriefing

At the end of every interview I checked with the participants on how they had experienced the interview and how they were feeling afterwards. A short debriefing conversation was held with each participant. No concerns were raised, and participants reported feeling comfortable to continue with their regular daily routine. A debriefing sheet was provided to each participant, containing information on low-cost therapy and support organizations in their area. An offer was extended to make contact via email over the 6 following weeks, should they feel affected by the interview in any way. No contact was made.

4.3.5. Transcription

The 8 interviews were transcribed manually by the interviewer using the voice recordings taken in the interviews. The voice recordings were saved immediately after the interviews in password protected audio files on my personal computer. No identifying information was stored with the recordings. The transcripts contained no

original names or identifying information and were stored using codes on my personal computer. My computer is also password protected.

4.4 Analytic process

In order to carry out the data analysis I followed the 6 steps prescribed by the IPA analysis method described by Smith, Flowers and Larkin (2009). I began by carrying out steps 1-4 for the first participant's transcript. I then moved on to step 5, repeating steps 1-4 for each of the remaining seven participants' transcripts. This led me to step 6, at which point I continued the analysis across all 8 transcripts (Smith, Flowers & Larkin, 2009). Below I describe how I used and applied these steps throughout my analysis process.

4.4.1. Step 1

In step one I read and reread the first participant's transcript while concurrently listening to the audio recording. It was helpful to hear the participant speaking and the expression and inflection in her voice, which gave another layer of meaning to the written word. It also allowed me to re-engage with my initial experience of meeting her, reminding me of what she was wearing, her body language and facial expressions. This helped me access the full experience of the interview while reading the text. Many elements of my participants' experience resonated with me and what I had gone through with my daughter. I found it challenging having to withhold my own similar experience until after the interview. My instinct was to share and compare stories, but I could see in the moment how this would have detracted from the focus on participants' accounts and changed the rapport in the interview. I was therefore

pleased that I had chosen to reveal my experience only afterwards, as I believe it would have been impossible for participants to speak openly without wondering about my experience or perhaps my judgements on what they were saying.

At the end of the interviews I greatly enjoyed the opportunity to disclose that I had had a similar experience, and to share that some of the points raised resonated with me. I felt rather nervous at being open for questioning but these conversations proved light and collaborative, and I feel they contributed importantly to balancing the power in the room. Being with women who had gone through an experience similar to my own gave me a taste of peer support, something that, unlike my participants, I had never been offered. I enjoyed the interview process and felt tremendously grateful to my participants for sharing their stories with me.

4.4.2. Step 2

I then moved into the initial coding phase. I saved a new version of the transcript with wide margins, leaving a column on either side of the text. The left-hand column was for my initial thoughts and notes and the right-hand column would be used later to capture emergent themes. As suggested by the IPA method (Smith, Flowers & Larkin, 2009), I read through the text once again, paying attention to any elements that stood out to me or sparked interest. At this point I tried to avoid questioning why these elements stood out and simply wrote down everything that came to mind, all the while keeping closely connected to the participant's description in the texts. When initially reading Vicky's transcript, the sense of aloneness was so apparent from her words and descriptions that I wrote 'alone' in the left-hand column. Through her story I could hear that no one was listening to her and that she felt ignored, and I wrote down these

impressions. I would return to these points later to explore them in depth but at this stage I was simply extrapolating any points that stood out as significant.

I then reread the text. However, this time I focused more on linguistic value, paying particular attention to details such as language, hesitations, pauses, and laughter. I noted instances where these elements occurred and any descriptive comments they evoked. For example, I noticed that Vicky laughed a lot throughout her interview. It struck me that she laughed while talking about painful and traumatic memories. I noticed this discrepancy, which made me wonder what meaning this laughter had for her; was it a way of controlling anxiety? I noted this behaviour in the margin together with the questions it evoked. When reading closely and listening carefully to the transcript, nuances like sighs and pauses become magnified. I noted moments where Vicky sighed and wondered if the sigh was telling me something her words perhaps could not express. Could her sigh enhance the meaning of her words?

Later, when I repeated step 1 for other participants I noticed how different elements stood out and created a picture of each mother's personality within the context of a similar experience. For example, Nicole used the word 'weird' several times. The lexical choice seemed unusual and perhaps colloquial in the context of the topic, but certainly evoked a sense of difference, otherness, and perhaps a sense of external judgment. Once again I jotted down these points to be explored at a later stage.

I was particularly struck by the adjectives the mothers used to describe their babies. These adjectives, though spoken so casually, provided great insight into their perceived fragility. I noted each adjectives that stayed with me and this led to a thread that later emerged across all cases and was explored in the findings. So much is expressed through speech style, language and gesture that goes above and beyond

the spoken word and it is these that give individual, unique meaning to a personal account of an experience. I wanted to pay attention to every aspect of expression from the interviews in order to create as holistic a picture as possible of each mother and her experience.

I repeated this process a third time, this time thinking more analytically about the text. I wrote down questions that had emerged about potential meaning in the text, language and descriptions. I thought about how participants' words and ideas build a picture of their overall views of their experience. By its nature, this stage also involved reflexivity and I questioned how my thoughts and reflections were building my relationship with the text, and how in turn this was building my analysis.

I recognise that I singled out certain elements from the text which seemed important to me. Another researcher engaged with this same text might have homed in on different aspects of the experience. Therefore, while the ideas extracted emerge directly from the data, they are also the product of a degree of selection and prioritization. My choices of what seemed important may have been influenced by my own views and experience. Many of the experiences recounted by the participants resonated with me, resembling what I remember of my first year of mothering. For example, I too was terrified that my baby would stop breathing in her sleep and I also felt responsible for protecting her from contagion and illness. In order to be sure which views were mine and which belonged to my participants I engaged in a constant cycle of reflexive questioning, checking to ensure that the emerging meaning reflected the participants and the overall experience. However, my personal knowledge of this journey allowed me empathize closely with their experiences, enabling me to interpret their experiences in more depth.

I redid this process several times until I felt immersed in the data. An example of this, taken from my analysis of Vicky's transcript, appears below. All examples demonstrating my research process are taken from Vicky's account in order to illustrate a clear progression of the analysis process.

Table 4.2. Example of initial coding phase

Initial comments	Transcript 1 (Vicky)	Themes
Laughing. Not funny What does the humour provide? Absurd? 'Writ large version'= similar but larger, more obvious, Comparing to others Different from the norm. Manual doesn't apply Not knowing what to do. Feeling clueless, unable, incapable, helplessness, unprepared, unskilled Alone unsupported Ignored Nowhere to belong Feeling unsupported. Nowhere to turn to for help Does this mean she is not important? No one cares Unknown, unusual. No one to turn to. No support. Difficulty breastfeeding	Hahaha Haha, You're actually picking us up Um, So umm, the, I think, erm, i..it's kind of a…a.. writ large version of anybody's first isn't it you know your sort of bring them home and think what am I supposed to do with them? But you bring them home and you really thinking what am I supposed to do with them. You're kind of, the thing being, though but that because you've been in hospital you've kind of fallen through the cracks, so the um, special care unit doesn't want to know you anymore, postnatal doesn't want to know you anymore. Because I will still ill as well. Erm, The health visitors aren't, don't know anything about premmies…	

4.4.3. Step 3

In step 3 I began to look for emergent themes, focusing more on my comments rather than the whole initial transcript. As I had been so meticulous in keeping closely to the text, I felt comfortable working with the notes I had generated. I also knew I would eventually connect any final analytic thoughts back to the text, which helped me feel

secure in the process. While reading through my comments certain key elements began to stand out. I noticed how some comments were connected or could be drawn together to build a broader picture of the participant's feelings and experience.

I began to look for connections between themes and group them into clusters, applying some of the techniques adumbrated by Smith, Flowers and Larkin (2009), such as abstraction, subsumption, numeration, polarization and function. To assist with this step I wrote the emergent themes into a new table, on which I could look at them all together on one page. This helped me identify connections between elements within the case and I used colour coding to signify connections between comments. Different colours were used to represent different connections; for example, I used green where abstraction applied and comments or themes could be drawn together because they were similar or identical; I used orange for themes where subsumption could be applied and themes could be merged together under one superordinate theme because they all related to the same concept or experience. Blue was used for themes or words that came up repeatedly where numeration had been applied; for example, the word 'weird' for Pam or words like 'tiny', 'fragile' and 'delicate' to describe the baby. Purple was used for function, where themes provided a function within the case; for example, laughter and the function of humour for Vicky. I found few opposing themes where polarisation applied but applying this technique did help identify stand-alone elements when looking across all cases during step 6.

In a second column I grouped all the same coloured comments together in separate groups. I then gave thought as to what these groups of themes represented and in a third column, I began to write down options of labels for the groups, which became my

superordinate themes. I was naturally also aware that this was now evolving into a picture being drawn by my interpretation of the text.

The emergent themes all derived from my initial comments and ideas. Therefore, the themes, although 'emergent' from the data, are also the product of my initial interpretations of the data and my engagement with the participants from the beginning of the process. Just as the initial note-making process was subjective, the process of comparing and contrasting themes was also impacted by my views and assumptions. I found IPA techniques helpful here, as seeing common themes or ideas and words repeated across cases sometimes provided confirmation that the themes were grounded in the text. For example, the theme of peer support was salient across all cases. It was easier for me to attribute this theme to the text because I myself had not experienced peer support. In fact, when I heard how my participants valued their peer support I felt a sense of loss, understanding for the first time that this was something I had missed out on.

The origins of some other themes were more difficult to pinpoint and took longer to decipher; one such was the tiger mother theme. In the interview, I had initially understood Angela's reference to a 'tiger mother' to imply the fierce protectiveness of a mother tiger for a helpless cub. However, I later discovered by chance that the term 'tiger mother' achieved common currency only after Amy Chua (2010) popularized it in her book 'Battle Hymn of the Tiger Mother' to describe a strict and relentless parenting style common in Chinese culture that pushes children to succeed. This caused me to question whether I had misunderstood Angela's reference and therefore interpreted the theme incorrectly. With this new knowledge I reread Angela's transcript to see what would emerge. In my view, Chua's concept of a tiger mother did not match

the other words and expressions Angela had used to describe her baby or her feelings as a mother. My interpretation of the term ‘tiger mother’ was more representative of Angela’s experience in the context of her interview. It took a lot of reflexive consideration and returning to the text before I felt confident to go ahead with this interpretation in the knowledge that it represented Angela’s overall experience.

These themes sometimes changed and I welcomed the fluidity of the process, moving themes and groups of themes around a number of times until it felt that everything fitted in its rightful place. I was then ready to move on to step 4.

An example from the analysis of Vicky’s transcript appears in Table 6.2 overleaf. This table shows how the analytic process developed from step 1, as seen in Table 5.1 above, to step 3 where comments in the left-hand column are considered collectively and drawn together to create concepts reflecting the participant’s experience.

Table 4.3. Example of emergent themes in step 3

Initial comments	Transcript 1 (Vicky)	Themes
Laughing. Not funny What does the humour provide? Absurd?	Hahaha Haha, You're actually picking us up	Humour as a defence
'Writ large version'= similar but larger, more obvious, Comparing to others Different from the norm. Manual doesn't apply Not knowing what to do. Feeling clueless, unable, incapable, helplessness, unprepared, unskilled	Um, So umm, the, I think, erm, i..it's kind of a…a.. writ large version of anybody's first isn't it you know your sort of bring them home and think what am I supposed to do with them? But you bring them home and you really thinking what am I supposed to do with them. You're kind of, the thing being, though but that	Feeling unskilled, unprepared Feeling different
Alone unsupported Ignored Nowhere to belong Feeling unsupported. Nowhere to turn to for help Does this mean she is not important? No one cares	because you've been in hospital you've kind of fallen through the cracks, so the um, special care unit doesn't want to know you anymore, postnatal doesn't want to know you anymore. Because I will still ill as well. Erm, The health visitors aren't, don't know anything about premmies…	Alone Closed out Lost
Unknown, unusual. No one to turn to. No support. Difficulty breastfeeding		Helpless

4.4.4. Step 4

In step 4 I created a table of the superordinate themes for each participant. An example of this table for participant 1 is shown below:

Table 4.4 Table of superordinate themes

Superordinate themes	**Emergent themes**	**Page/line**	**Keywords/ phrases**
The second set of horror	Thrown into mothering Keeping the baby alive	1.3 25.4	"We came home very suddenly" "…to keep him alive"
The isolation of limbo	Helplessness Responsibility Feeling alone Coping with others expectations Cycles of recovery and fear	3.7 1.27 7.25 5.9 10.34 8.48	"Nobody knew how to help" "Nowhere really to turn to" "So there was kind of no one." "Everyone else thinks" "You're fine" "It's a long time 20 seconds…we got used to it"
The threat of bonding	Difficulty bonding Waiting to feel connected	24.31 14.11	"Im not sure I did bond" "I'm still waiting"
What does a mother feel like?	Feeling like a mother What does being a mother feel like? Lingering fear of loss Hope	14.3 14.3 22.21 18.26	"Oh I still don't think Im one!" 'Im your mother? Really?" *"That one worried me for a very long time"* *"it looks okay, he he, he is okay"*
The need for support	Reaching out for help Peer support	20.33 18.7	"I did need something" "Gone nuts without them"

4.4.5. Step 5

After I was satisfied with my progress on the first case, I took a few days' break to clear my head. I then repeated the process outlined above for the second participant's transcript and continued this process until all the interviews had been analysed in this way. For every case during this step I was conscious of the need to cease reflecting and remove myself from the data so that I could embark on the next participant's account with a clear mind. This was helpful, but of course I remained mindful to bracket

any pre-existing ideas from the previous analysed interviews to keep each analysis as rooted in the text as possible (Smith, Flowers & Larkin, 2009).

4.4.6. Step 6

Once all the interviews had been analysed according to the above process, I had several themes and superordinate themes to work with. In step 6 I carried out the task of looking for patterns across the cases (Smith, Flowers & Larkin, 2009). This included similarities and connections between themes, but also sometimes equally important strong stand-alone themes that highlighted uniqueness. I used the same process as detailed above, plotting all the superordinate themes into a new table and using colour coding to signify connections between superordinate themes and concepts. One of my main concerns in this step was to make sure that the initial pilot study with my first participant, Vicky, was not exerting an overbearing influence on the superordinate themes. Some of the themes that initially emerged from Vicky's case carried through to the final superordinate themes, such as 'the second set of horror' and 'the isolation of limbo'. I wanted to be certain that this accurately represented the whole participant group and was not just the result of my analysis being influenced by prior interviews. I traced the emergence of the relevant themes from every transcript to ensure they were grounded in the text and checked to confirm that my interpretations matched the context. I found encouraging evidence for my themes, such as Pam's description of homecoming as 'a whole second cycle of scared'. I also revisited diary entries made between interviews to check my thoughts and potential biases between interviews. This process satisfied me that the reason the themes had carried through was because they were indeed strongly representative of the experience and applied to all the mothers in the group.

Surveying all the themes, patterns began to form, and a picture began to emerge that was shaping into a rich collaborative expression of the overall experience of the mothers. This picture remained fluid for some time and I was accepting of this. For example, the first three subthemes under the ‘second set of horror’ seemed to overlap. Originally there were two sub-themes, labelled ‘keeping the baby alive’ and ‘responsibility to save the baby from dying’. I grappled with this because I felt there were certain nuanced elements of each subtheme that made the essence of the theme both different and important to include. Initially I chose to include both, but I finally decided to merge them into one subtheme under the title ‘responsibility to keep the baby alive’. I am confident that the final version of this subtheme incorporates the important elements of both original themes.

When themes began to feel constant for an extended time I felt ready to approach writing up my analysis. At this point I gave careful thought as to whether I wanted to share my findings with my participants before writing up my discussion. Sharing the findings would have provided an opportunity for participants to clarify or confirm certain themes and might have enhanced the validity of the study. However, I was concerned that participants would find it difficult to read their experience printed in black and white and that they might be left feeling exposed and vulnerable. They would have been reading the findings alone and I would have been unable to provide a sufficient level of support for them after the reading. This did not seem to be in their best interests and I therefore decided against this. I have offered to send the thesis to them when it is complete. Reading the synthesised depiction of the experience of the group is likely to feel less intense and their anonymity will be apparent and comforting.

4.5 Ethical considerations

This research project was only put into action after it had been evaluated and approved by the university's ethics committee. I have conducted my research in accordance with the British Psychological Society's Code of Research Ethics as well as the Research Ethics guidelines set out by the School of Science and Technology as stipulated by my course (Bps.org.uk, 2015; Ethics.middlesex.wikispaces.net, 2015). Certain ethical considerations needed to be taken into account and I have addressed these accordingly.

A purposive sample was collected. The sample consisted of 8 mothers over the age of 18 who had given birth to single babies between 28 and 32 weeks' gestation. Due to ethical considerations relating to the wellbeing of prospective participants I did not include anyone who was currently pregnant or actively trying to conceive. This exclusion criterion was clearly mentioned in my participant information sheet. Due to the sensitive nature of my interview material, I was aware that some participants may have found the interview distressing. To ensure the wellbeing of my participants I spent time with them explaining the nature of the material that was likely to be discussed, and what would be expected of them. I reminded them that if they were to find the interview distressing or upsetting, they were welcome to terminate the interview at any point. I had not planned to include women who might be considered vulnerable for any other reason.

4.5.1 Risk assessment

Although of a sensitive nature, my interview material would not be classified as

invasive. My research question does not specifically address extremely private phenomena that could cause a participant to feel exposed or vulnerable. I therefore did not foresee any specific problematic ethical considerations related to this research (Ethics.middlesex.wikispaces.net, 2015).

However, discussing the experience of mothering a premature baby is considered sensitive material likely to evoke unpleasant feelings in participants that could result in anxiety and low mood (Smith, Flowers & Larkin, 2009).

Aware of this, I took considerable care to ensure the protection and wellbeing of my participants throughout the interview process by checking with them throughout the interview and by remaining attentive to any signs of distress. For example, I remained aware of possible changes in speech and body language or any other visible signs of distress or panic. If I had felt concerned at any point, I would have reminded the participant of their option to break off at any time. However, this was not necessary in any of the interviews. Complying with Middlesex ethical guidelines, the following procedures were also put in place to ensure maximum consideration for participants' safety and respect throughout the research process (Ethics.middlesex.wikispaces.net, 2015).

4.5.2 Welfare

I put in place a process should the very unlikely event arise of a child protection or welfare issue. I planned to discuss any concerns immediately with my supervisor and follow the recommended safety procedures. Before beginning the interviews, I clearly defined the parameters of confidentiality, explaining that any information that might

cause concern regarding safety of self or others would need to be shared with relevant professionals. Further information regarding confidentiality is set out below.

4.5.3 Beneficence

I owed a duty of beneficence to the participants in my study (Bps.org.uk, 2015). My intention in this research was to develop ideas that will hopefully make a positive contribution to the future welfare of parents of premature babies. I had no intention of causing harm to participants in any way and there was no element of this study that could be seen to lead to participants being harmed. By following ethical guidelines and rules of good practice I did my utmost to prevent any harm coming to my participants as a result of my research.

4.5.4 Informed consent

I ensured that every participant was provided with an information sheet containing full details of the study and their participation in it. I ensured that the aims, process, and method were described simply and clearly. I also ensured that the participant had enough time after reading this information to make an informed and unpressurised decision. Participants were made aware of their freedom to decline participation without prejudice to themselves. To ensure ongoing consent I checked with the participants throughout the research process.

4.5.5 Written consent

Each participant was required to sign a written consent form that clearly outlined the parameters of their participation and any other details potentially relevant to their participation in the study. Only those agreeing to give written consent would have been allowed take part in the study, but all were happy to sign the consent forms.

4.5.6 Awareness of deception in the research method

My research process did not require any form of deception and the process remained honest and transparent throughout.

4.5.7 Confidentiality

Participants were ensured of complete confidentiality during the research process. This pertains to their anonymity being protected throughout the process and confirmation that their data would not be shared with any parties unrelated to this study. This has been ensured by anonymizing participants' details, keeping identifiable details separate from written and audio interview data, and keeping transcripts and recordings in a locked filing cabinet.

I have made participants aware that there must be limitations to confidentiality, to protect their wellbeing and that of other members of the public, in accordance with ethical standards. I explained that this meant that if during the interview it became apparent to me that the participant was at risk of harm in any way, to themselves or to others, I would need to share this information with other professionals in the interests

of their safety and support. I made clear that I would only do this with their knowledge and that I would only share their information with relevant professionals able to assist and provide support under the circumstances.

4.5.8 Right to withdraw

Participants were made aware of their right to withdraw at any time without any negative consequence to themselves.

4.5.9 Debriefing

A full post-interview debriefing session was offered in accordance with Middlesex debriefing ethical guidelines. I was aware that participants were not obliged to accept this opportunity, but all were happy to go ahead with this. The debriefing addressed any negative feelings participants might have encountered as a result of the research, as well as the clarification of any further details of the research. The aim of the debriefing session was to ensure the participant left the interview feeling at least as good as when they arrived. I felt confident that this was the case when each participant left. I explained that I would be available to discuss the study with them and to monitor any negative effects or misconceptions for 6 weeks after the interview.

During the debriefing session I provided and explained a full sheet of further resources participants could access should they need further support. This sheet included information on options for low-cost therapy in their area, relevant online support groups and specialist organisations such as Bliss. Bearing in mind that there are few specialist resources for mothers of premature babies, I supplied information on the most relevant

resources available.

I am confident that following the above framework has ensured safety and respect for all my participants. I am also confident that working within this framework has helped me remain aware of possible ethical considerations that could have arisen throughout the study.

4.5.10 Risk assessment for the researcher

I have also considered my personal safety throughout the research process. In order to do this I ensured that the interviews were held in a formal setting with other people close by, such as rented rooms in a building with a receptionist and purpose-built therapy rooms with a receptionist at hand. Interviews were set at a time when administrative and security staff were present from arrival to departure from the premises. This ensured safety for both researcher and participant. I also set boundaries as to how and when participants were able to contact me. I did not share personal details other than my phone number, email address and details of my course.

4.5.11 Personal ethical considerations and practical applications

As the mother of a premature baby born at 29 weeks, the research process of this project was likely to affect me. I was aware that hearing other mothers' accounts of their difficult experiences might bring up difficult emotions and remind me of difficult personal experiences. This created several potential ethical issues that I took care to address. I needed to attend to my own wellbeing, ensuring that I had put support in place to deal with difficult interview experiences. I discussed all my interview

experiences in personal therapy, which I continue to attend. My therapist was aware of my plans from the start of my research process. He had agreed to provide this support from the beginning and has done so throughout my research process.

4.6 Reflexivity

It was important to consider how my personal connection to the subject could potentially affect the research process. It is possible that my own experience, as well as the way I experienced the interview process, could have impacted my analysis and interpretation of the data, with implications for the outcome of the study (Smith, Flowers & Larkin, 2009). An important aspect of addressing both these concerns was to ensure constant reflexivity throughout the research process.

Interpretative Phenomenological Analysis places great focus on the role of the researcher in the research process. I feel that my choice of methodology has supported me in an effort to remain aware of the double hermeneutic and keep a focus on bracketing my own feelings, biases and expectations throughout the process (Smith, Flowers & Larkin, 2009). As Giorgi (1985) points out, phenomenological commitment encourages continued self-reflection, uncovering personal values and intersubjective experiences that can shed light on the on the research.

As Finlay (2003) suggests, articulating my theoretical position motivated critical thinking throughout the research process. I was encouraged to think reflexively about my own role in the research, as well as about other factors such as the context of the interviews and interpersonal and cultural influences. This encouraged a multilevel

reflexivity that encouraged me to continuously ask myself questions throughout the research process (Finlay, 2003).

To assist with this, I have kept a personal research journal since the beginning of my research process. Writing this journal has helped me explore my own feelings from the beginning of my research journey and throughout the research process up until this point. Taking time to reflect on my experience of the process has helped me monitor how the research process has affected my own emotional state and in turn, how this could affect the research process (Smith, Flowers & Larkin, 2009).

I have written in my journal before and after every interview, and through every stage of the interview process. By doing so I was able to refer to these entries during my data-analysis phase. This has helped ensure that my themes have emerged directly from the data and are not influenced by my personal experience. By remaining aware of these processes I have been able to bracket my own biases and prevent them from affecting my interpretation and analysis of the data, ensuring that all findings are grounded within the data (Smith, Flowers & Larkin, 2009).

Interpersonal dynamics can also influence the research process. Being aware of the power dynamic between researcher and participant has been important in understanding how this may have affected both the data and the analysis (Wilkinson, 1988). It became apparent during the interviews how strongly these women want their voices to be heard and their experiences acknowledged. This evoked a surprising sense of responsibility within me to give an accurate and compassionate account of their stories and do them justice. During the research process this heightened sense

of responsibility helped me keep the analysis grounded within the data and keep the quotations linked as closely as possible to the context within the text.

4.7. Disclosing my personal experience

I had to consider carefully whether I was going to disclose to my participants that I too had given birth to a very premature baby. Although I was inclined to share this information with them, I was aware that wondering about my experience could inhibit them from being fully open about their own experience. On the other hand, it was possible that knowing I had shared this experience might have made them feel more comfortable (Parker, 2011; Smith, Flowers & Larkin, 2009). I chose to disclose my experience after the interview and during the debriefing process. In this way the interview data was not affected by this knowledge and participants also had a chance to share their thoughts or ask me questions they might have had. I prepared this disclosure beforehand and ensured that the discussion was brief and contained, in order to uphold a professional boundary.

4.8 Validity

I used Yardley's (2000) four principles of validity as a guide to help me check my work throughout the process. Here I will discuss her two principles of sensitivity to context, and commitment and rigour. My concluding chapter discusses her last two principles: transparency and coherence, and impact and importance. I have chosen to split this discussion as I believe the final two principles are more meaningfully discussed after my analysis and discussion have been read.

4.8.1 Sensitivity to context

Yardley (2000) suggests that sensitivity to context is an important aspect of ensuring validity in qualitative research. In the outline of my analytical procedure above I have demonstrated how I applied sensitivity to context. This began in the initial stages of recruiting participants through Bliss and acquainting myself with participants' environment. I also did this by meeting the mothers at the Bliss Prematurity week tea party. I continued to show sensitivity to context in the way I arranged my interviews, setting them up in neutral spaces that were local and easily accessible for the participants. I was continually reflexive throughout the interview process, and intent on remaining mindful and respectful of participants and their experiences. As demonstrated above, this sensitivity continued throughout the analytic process by keeping the analysis grounded within the text. Discussing my findings within the context of the literature and previous findings also evidences awareness and sensitivity to context (Yardley, 2004).

4.8.2. Commitment and Rigour

Yardley (2000) also comments that commitment and rigour are important in assuring validity in qualitative research. The way I have shown sensitivity to context can itself be considered as testifying to my commitment to the research process. Adherence to ethical codes and the welfare of participants further supports this. I have striven to master the principles of the research method and follow these steps as advised, showing further commitment to the research process and to producing robust research (Yardley, 2000).

The sample for this study was chosen purposively, using very tight parameters. Although this made the recruitment process longer, it provided me with a homogenous sample that would generate comparative results. The sampling procedure and inclusion criteria took the welfare of participants into consideration by ensuring that a significant time had passed since the trauma and that they were not currently pregnant or trying to conceive. A further element that increases validity is that the analysis has been grounded in the text; extracts of transcripts have been provided to support this (Yardley, 2000).

4.9 Conclusion

This chapter has demonstrated that this research project has followed carefully thought-out and robust planning and procedure from the conception of the research question to the analysis of the findings (Yardley, 2000). It has been shown that the IPA method was chosen after careful scientific and philosophical investigation. It has also shown how the research process and procedure have followed the required steps while adhering to all necessary ethical and practical considerations (Smith, Flowers & Larkin, 2009). The use of reflexivity has also been demonstrated and its role in the above processes has been highlighted (Finlay 2002).

5. Findings

5.1 Introduction to findings

A rich data set from 8 semi-structured interviews was analysed using the steps prescribed by Interpretative Phenomenological Analysis. Table 5.1 shows participant data that provides a brief introduction to the 8 mothers who participated in the study.

Table 5.1 Participant demographics

Participant	Ethnicity	Age	Gestation at birth	Child age at interview	First time mother	Relationship status	Baby health at discharge
Vicky	W/O	44	31 weeks	4	Yes	Partner	Healthy
Nicole	B/O	25	28 weeks	3	Yes	Single	Healthy
Heather	W/B	40	29 weeks	5	Yes	Partner	Healthy
Pam	W/B	42	30 weeks	4	Yes	Partner	Healthy
Beth	W/B	38	28 weeks	5	Yes	Partner	Healthy
Annita	B/O	36	28 weeks	5	Yes	Partner	Healthy
Angela	W/B	37	29 Weeks	4	Yes	Partner	Healthy
Eleanor	W/O	40	29 Weeks	4	No	Partner	Healthy

The process of analysis yielded 27 superordinate themes that stood out as representative of the mothers' overarching experience. In the next stage of analysis, when the themes were considered all together and in relation to each other, connections and similarities began to emerge, drawing certain themes into clusters. The themes in each cluster worked together to create a picture of a strong overarching

element of the mothers' experiences and these were then designated superordinate themes.

The themes are represented in Table 5.2 below, which shows how the 27 superordinate themes that emerged from the data during the analysis process were grouped into 7 clusters. The right-hand column shows these clusters or superordinate themes, while the left-hand column shows the 'umbrella' title or hypernymic theme that encapsulates the essence of the data cluster.

Table 5.2. Master table of superordinate and subordinate themes

Superordinate themes	Subordinate themes
The second set of horror	• Thrown into mothering • Feeling unskilled and unprepared • Fear of the baby dying • Responsibility to keep the baby alive • Delayed resolution
The isolation of limbo	• Fallen through the cracks • Feeling dismissed • Feeling completely alone • Feeling different • Perceptions of the baby • The importance of Peer support
Attachment to the NICU	• Needing guidance and support • Acknowledgement of the trauma • Gratitude and acknowledgement
Feeling like a mother came later	• A shock transition • Mothering on autopilot • Feelings of guilt and failure
Bonding in the shadow of the threat of loss	• A different type of bond • The tiger mother bond • The importance of reciprocity
Mourning an intangible loss	• Permission to grieve • Loss of trust in the body • Loss of control over the baby
Mothering in the wake of trauma	• Rooted in the context of the NICU • Delayed processing of the trauma • A permanently changed worldview • The need for emotional support?

This chapter explores these themes in more detail, and their relevance is illustrated through quotations from the interview transcripts. As this is an interpretative phenomenological study, this chapter also includes the researcher's analytic

interpretation of the themes in order to generate a deeper understanding of the data and how it sheds light on the research question. Critical reflections will be interspersed throughout the analysis and these ideas with be developed further in the discussion chapter. The double hermeneutic and interpretative nature of this process means that the interpretation is inevitably subjective to some extent. However, the continuous use of bracketing, self-reflection, and returning to the text has been applied in order to remain as close as possible to participants' experiences.

5.2 Themes

5.2.1 The second set of horror

This theme is taken from a quotation from Vicky's transcript. All 8 mothers described the period after hospital as terrifying; they felt a tremendous responsibility to keep their baby alive or save its life. Fears of the baby dying or becoming ill dominated the overall experience of the first few months, seeming to overshadow any enjoyment of their baby or their status as a new mother. All 8 mothers described how these fears continued throughout the first year and even beyond. Because this time-period has not previously been explored, this is a new finding.

> *"I think um, 'cos I think this sort of, for the parents of babies that are in hospital that's a whole set of horror and all the rest of it, and but there's then the sort of, the next set, when you're kind of ok, um, they then just leave you to it."* (Vicky, 10:20)

The superordinate themes are discussed in more detail below.

5.2.1.1 Thrown into mothering

After a harrowing few weeks in the NICU, homecoming was a happy milestone. However, participants remember feeling surprised at how terrified they felt when this milestone was finally reached. They remember that their babies' progression from being medically dependent to being ready for discharge happened very suddenly. The transition from the supportive and medical environment of the NICU to being at home alone with the baby therefore happened without significant mental or practical preparation. It was as if they had been thrown into their role as mothers. Describing the first few days and weeks at home the mothers made comments such as:

> *"Um, surreal, ha ha ha, I guess, um, we came home very suddenly"* (Vicky, 1:3)

> *"Okay. So, I remember the day they said we could bring her home and I felt a bit like 'oh . . . okay'. We'd been really looking forward to that day and suddenly it felt quite sort of scary. So we actually asked for an extra day in the hospital, I think to make sure we understood everything and knew everything and were ready."* (Beth, 1:6)

The sensation of terrifying aloneness and vulnerability was a common factor:

> *"Um . . . um . . . you're kind of on your own all of a sudden."* (Angela 1:14)

"The first night we brought her home was terrifying, because although we did the stay in for a day and the night you knew the nurses were right next to you. So it was a bit scary to bring a baby home who was that tiny." (Anita, 1:5)

This feeling of suddenness can be linked to the mothers' difficulty in fully engaging with the possibility of bringing their babies home before this point. After facing the possible loss of their babies, perhaps it was too frightening to hope or expect that they might come home until the day actually arrived:

"And then of course there's kind of, you've nearly lost him so you're just kind of waiting, to make sure that you're actually gonna keep him, I think, as well. . . so, ya, maybe a difficulty in uh, in adjusting to that, that you know, when you've lived with the idea of possible loss." (Vicky, 12:22)

"So it had been a really long slog and there were many many times when we weren't sure whether we would get to bring her home." (Heather, 1:7)

Nicole's disconnection from hope was more conscious and absolute:

"You've kind of got to say goodbye to . . . you know, this perfect image you have, and it's almost like your child has died in a way which even though the child in your head is not a real child, but it's that like expectation and your hopes and dreams for them, you kind of have to say goodbye, and you've just got to say well, we'll see what happens, because you can't really hope." (Nicole, 17:11)

These reflections convey the mothers' fear of loss during the hospital stay, which overshadowed their experience of bringing their baby home.

5.2.1.2 Feeling unskilled and unprepared

There seemed to be a common feeling of relief when the hospital stay was over, and the mothers were able to come home with their baby. However, paradoxically they also reported feeling completely unprepared and unskilled to take care of their tiny baby alone at home. After being guided and monitored by hospital staff for the first few weeks, they were now left to take care of their babies on their own. Some reflected that this experience might be no different from that of other new mothers, but for these mothers there was a particular focus on finding it difficult to trust in their baby's ability to function and survive on its own.

> *"I think, erm, it's kind of a writ large version of anybody's first isn't it? You know, you sort of bring them home and think what am I supposed to do with them? But you bring them home and you're* ***really*** *thinking 'what am I supposed to do with them?'"* (Vicky, 1:19)

The reassurance provided by the hospital technology was no longer a support, leading to heightened anxiety about the baby's chances of survival:

> *"When he came home . . . we went and got a sensor mat and everything, you know, all that we could do, because it was just like I needed to see numbers or*

a chart or something, just to tell me that he was like working properly as a normal human being you know." (Pam, 2:21)

"So just getting to our home surroundings was amazing. But at the same time, you don't have all of the props that you kind of got used to in NICU. So that means um. . . . anything, from nobody being there to tell you if you're doing things right . . ." (Angela, 1:8)

All 8 mothers expressed a feeling of being unprepared and lacking the skills and ability to mother the baby. This was described and interpreted in different ways by each mother, but the common denominator was a need for guidance, instruction, and reassurance that they were caring for the baby in the right way. Feeling unprepared and unskilled created anxiety - a fear that their quality of care was insufficient to protect the child from getting sick or dying.

"But you just worry . . . will I be able to do this? And will I spot it correctly? I think they were kind of supportive there, but it's just scary when you're talking about a child, you know . . . rather than you know, it's different if you take a computer home and you can't get it to work, but it's a bit different when it's your baby that you're taking care of, if it breaks and you need to fix it." (Pam, 4:2)

Three mothers described the experience of hearing their baby cry for the first time and remembered feeling shocked, helpless, and unequipped to comfort them. Their immediate response was to look to others for guidance and advice, as they had done in hospital, but at home there was no one around to help them. They seemed to lack

an instinctive response or perhaps could not trust that their instinctive response was good enough. Later we will see how the mothers described their bond as a primal desperate desire for basic survival. Perhaps the initial focus on survival left no space to develop soothing responses:

> *"She never cried in the NICU and I don't know if that's a premature baby thing. I don't remember babies ever really crying. It was always quite quiet and just the machines. So I was feeding her in the night and she was crying and I was quite shocked and like, 'oooh, how I settle her? This is completely new'. I remember that vividly, really clear in my mind that night because it was like, 'Oh, wow. What do I do? My baby's crying! Why is she crying? What's this?' So that was yeah. That was quite interesting."* (Beth, 2:18)

> *"I think I was being so clinical, I never really, when she used to cry and she just needed me I didn't feel that need . . . to you know like . . . what do I do now? How do I deal with this? What I do? Right she is crying and all of a sudden going into this blind panic."* (Anita, 12:14)

After weeks of supervised parenting in the NICU, the mothers became accustomed to having a watchful eye over them. It was normal to have to ask permission to see, hold or touch their baby. Although at the time this had been experienced as difficult, it was the only way they had been able to relate to their child. They had also learned that holding or touching them at the wrong times could be detrimental to their development. Some mothers found those feelings hard to shed after their baby was well enough to come home and be held and cuddled at any time. They also struggled with the thought

that their touch or care could possibly harm them. This background of dependency – all they had ever known – explains the mothers' lack of faith in their own abilities. They had been mothers for weeks but had never had the opportunity to develop the skills to nurture or care for their babies. They also had had little opportunity to get to know their baby and learn to understand its needs and communication. Anita's insecurities are illustrated in the excerpt below.

> *"A lot of the times I would make plans and not go through with it because I'd think 'oh, I'm disturbing her routine and I might disturb her routine. You must stick to the routine.' Anything went out of routine and I panic . . . Was I affecting her eating? You know, she won't eat properly. Therefore, she would be cranky. She would be sick, she would be crying."* (Anita, 15:7)

All the mothers described feeling the need for guidance and instruction on how to care for the baby. Breastfeeding was a major element of this, given the struggle to develop breastfeeding with infants that could not yet coordinate the suck reflex with breathing and swallowing. The mothers found breastfeeding difficult and exhausting, and felt they needed guidance and help to establish what they felt should have been a natural process:

> *"You kind of, you know, all your questions, you sort of, have nowhere really to turn to. Breastfeeding was complete hell. Um, and nobody knew a thing about it."* (Vicky, 1:28)

> *"The first few months were horrible . . . (Laughing) looking back because it*

was like, you know, he wasn't, he didn't breastfeed to start with because well, he just couldn't. It was easier for him to take expressed milk from a bottle. So that made it just worse. . . . You had to express, and then you had to sterilize the bottles and then you had to feed him and then express again afterwards and get the next feed ready . . ." (Pam, 14:3)

". . . things like feeding you're kind of on your own all of a sudden having had a lot of breastfeeding support and I was tube feeding for a while. So on one hand, it feels great that you're independently feeding the baby, on the other hand, you don't have all of the support and props that you had in the hospital." (Angela, 1:14)

These reflections give an insight into the intensity of the mothers' emotional experience during the NICU stay. The raw descriptions capture the anguish of an experience all too often neglected or misunderstood by others. This anguish does not end with NICU discharge as is sometimes assumed. The initial trauma of the early birth experience and hospitalisation evidently influences the way these women relate to motherhood and how they mother their baby in the early months:

"When he got unhooked from the machines I started panicking that something might be going wrong. He might have stopped breathing or whatever, and I wouldn't know about it until something had bad happened, you know some damage had happened and I think that continued for a little while." (Pam, 2:17)

Couldn't sleep the first night because you are so anxious (Anita, 1:23)

Such fears are projected into the imagined future of the mother-infant relationship:

> *"Of course, babies will walk and talk. you never think that your child won't be able to do all these things . . . It's not something that you really think you could end up being in . . . that kind of world, and it's just it's a terrifying thing. . . . You don't know if they're going to be okay."* (Nicole, 19:6)

> *"But part of me still worried. What if her physical development wasn't right? What if she's autistic or there's something wrong, on the spectrum . . . what if she's not developing normally?"* (Anita, 3:3)

The salient feelings in these accounts are fear and anxiety. As the interviews unfolded, further themes began to emerge which capture the source of fear and anxiety and how this manifested in the months following homecoming.

5.2.1.4 Fear of the baby dying

All the mothers described an intense fear that their baby might die. This was in many cases rooted in realistic medical concerns related to premature babies. However, they also recognised an emotional element that they associated with their confrontation with the potential loss of their baby. This common thread suggests that after facing a traumatic early birth and the precarious state of the baby's health, the mothers struggled to develop a trust in their baby's resilience and ability to survive in the world unaided. The reality of existence means that that there is no life without the inevitability of death, and death cannot be predicted. This is as true of all babies as it is for all human beings. Most new mothers are not preoccupied with this fear and are focused

on the joys of their new baby and their new role as a mother. But these mothers of premature babies had reached a new, inescapable existential awareness through the experience of their trauma. Awareness of their limitations made them fearful of death and disaster and they lacked the tools to manage this fear and anxiety.

This fear translated into an intense sense of responsibility for their baby's safety. This can also be related to their feelings of personal guilt and responsibility for the early birth which will be discussed later on in this chapter. The following excerpts give a taste of the immense burden of responsibility these women felt for their baby's safety. These quotations resonate with the fear that constantly accompanied them throughout these months.

> *"The number of times I've had to see them perform CPR on him or I had to do it myself when he came home from hospital whilst I called an ambulance. Nothing can prepare you for that. And then if you don't have anyone to talk to about it, it's just going to stay inside you and it's going to eat away at you"* (Nicole, 14:10)

> *"I used to go and check on him before I went to bed to feel him, make sure he was still breathing. If he'd slept through the night. I'd panic, you know, has something happened to him and I would want to go in there and check on him, but not wanna go in case, you know, something happened during the night."* (Pam, 3:7)

Some mothers laughed when recounting these fears, suggesting that retrospectively they found their reactions excessive or even absurd. However, they were recounting medically serious incidents, suggesting that their precautions and fears were not completely inappropriate, and that their laughter was a form of defence mechanism, protecting them from overwhelming anxiety. For example, when Beth placed the rain cover over her daughter's buggy when they went out, she was doing it to protect her baby from infection and illness, a reasonable precaution for a baby with a lowered immune system. Yet having emerged from that traumatic state, Beth retrospectively purports to find that behaviour quite amusing. This suggests a nervous attempt to control an otherwise uncontrollable anxiety. The passage of time and Beth's emergence from her trauma state allows her to look back at her behaviour through a different lens and recognise her heightened fear, and her detachment from her usual sense of judgment and mode of functioning in the world.

This dichotomy depicts the uncertainty of the first year for these mothers, who are caring for a baby that is not clinically sick yet is fragile and susceptible to illness and setbacks related to their early birth. It was clearly confusing for these women to make sense of their intense emotional responses:

> *"Because it does seem quite funny. It must have looked quite funny to see a lady walking around with a pram with a rain cover on and it's not raining."* (Beth, 1:26)

Beth is obviously using the term ‘funny’ in the restricted sense of ‘odd’, rather than comic, in this quotation, just as Pam uses the expression ‘bizarre’ to imply the same sense of oddness:

> *“Yeah, then I'd be worried if he hadn't woken if he sort of like slept in a little bit I would be a bit worried. Yeah something that I've been through, just neurotic really, I suppose looking back”* (Pam, 3:12)

> *“It’s bizarre, it’s just bizarre . . . I don't, I'm sounding like a complete lunatic saying this.”* (Pam, 5:30)

5.2.1.3 Responsibility to keep the baby alive

From birth all 8 babies required medical support to help them breathe, eat, and regulate their body temperature, all of which were essential for survival. In all 8 cases the babies’ transition from medical dependency to discharge-readiness was sudden and brief. There was little time or opportunity for the mothers to adjust to the idea of their baby being strong enough to survive outside the NICU. The burden of ensuring their babies’ survival seemed to these mothers to have been suddenly and unexpectedly thrust on them and all felt utterly unskilled and unprepared for the task:

> *“You just start worrying . . . that something’s going to happen and we're going to be at home and I'm not going to know what to do and you know that sort of stuff”* (Pam, 3:4)

"We actually asked for an extra day in the hospital, I think to make sure we understood everything and knew everything and we're ready. Even, I had to ask them to show me how to give her a bath sort of thing. And then we got her home. . . . And so it was lovely and it was exciting, but it was quite daunting." (Beth, 1:8)

This burden of responsibility precluded any enjoyment in the new baby:

"It's sort of like I need to make sure that he's alive and he's being fed and it was just sort of there was no real chance for me to enjoy him." (Nicole, 15:19)

Even Eleanor, who was not a first time mother, felt ill-equipped and out of her depth:

"It could feel like . . . they say he's fine and if there's something that seems whatever like, you just want to know . . . how should he sleep? How should he? . . . You know? Just, I wanted to talk about all those things." (Eleanor, 2:12)

The responsibility to keep their baby alive was experienced as an ongoing pressure to feed the baby and make sure it was growing and putting on weight.

"I can't entirely remember, the first weeks to be honest, other than thinking I have to feed him, and um . . . He didn't have the suck reflex when he came home. . . . He probably, he couldn't do the, even the breath; swallow; suck . . . because he didn't know how to put everything together. Nobody knew how to help." (Vicky, 2:2)

"I was always scared that I wasn't producing enough milk because I wasn't initially . . . because it's that fear that you never feed the baby enough and when you don't see the gain." (Anita, 2:14)

Another aspect was the vigilant monitoring of the baby's breathing and readiness to intervene and resuscitate if necessary. They were also vigilant about protecting the baby from infection and illness:

"This is a baby that has . . . he has to be cared for. He has to be cared for a little bit more than the other babies because he had a more difficult start to life. You know, we've got to sort of got to make sure that he's progressing um properly, um and it just it was very difficult." (Nicole, 3:6)

"He just wouldn't breathe for seconds at a time and we'd count 3, 4, 5, 6, 7um, and by 10 seconds he'd always breathe but there are one or two times where he didn't and then one time, um, he like started getting a bit limp and I thought a bit blue so we rushed into A and E and it was fine." (Angela, 2:29)

Thinking about these fears, all 8 mothers also remembered feeling a great sense of responsibility to save their baby's life if anything went wrong. In the hospital NICU, the life support machines provided reassurance that specialist help was at hand in an emergency. As noted above, the baby's liminal position between health and dangerous fragility generated paradoxical emotions:

"They said go and breathe really loudly next to him, and it has to be the mother who goes and breaths, and that will . . . kick it off again. And after a while it seemed to, it did seem to, I don't know at first, but it did seem to later, it sort of reminded him to breathe." (Vicky, 13:25)

"I needed to see numbers or a chart or something just to tell me that he was like working properly as a normal human being you know." (Pam, 2:24)

"Oooh, is he gonna be alright you know? And more importantly, what am I going to do if something happens, you know?" (Pam, 3:22)

The mothers described the absence of the machines as a loss; they had no way of establishing whether something was going wrong, or indeed reassurance that everything was okay. After discharge they seemed to assume the role of monitor, closely watching and checking the baby:

"With *a premature baby you're just thinking what if you know, because you've lost the monitors . . . You don't have the noises and the sounds anymore . . . Suddenly it wasn't there anymore and you're so used to having something to look at all the time. So that was a bit frightening because you can sort of . . . oh no, what if something was wrong?"* (Anita, 1:8)

"It means none of the beeping breathing monitors, which is a great thing, and those sounds were not great for anyone. But at the same time, we didn't buy

our own breathing monitor and you're kind of waking up in the night thinking 'is he breathing?" (Angela, 1:10)

"I was worried about all different things because we had that mat in the hospital where I think how it worked . . . that if the if the breathing pauses for a certain amount of seconds it beeps . . . but I had to get used to the fact that we didn't need that. So yeah, this is sense of like dependency and we're letting go of that dependency." (Eleanor, 1:9)

Through the mothers' words and body language, I could sense the weight of this responsibility and the constant fear it invoked. Being on guard day and night sounded draining and exhausting. There was little reassurance available to these mothers to contain their fears and moreover, there was a long way to go before this would be possible. Whilst this responsibility clearly had a physical basis, it may also include a psychological element. It can be viewed as a way to gain some sense of control over their babies' health and survival. In a fearful, uncertain time this perceived sense of control was comforting whether real or imagined.

5.2.1.6 Delayed resolution

As the interview questions continued, spanning the baby's development over the first year, it became clear that all 8 mothers experienced continued stress and anxiety. As one struggle ended, the next began. When breastfeeding or bottle feeding were finally established, weaning became a challenge. When weaning had taken off satisfactorily, sitting, crawling, and walking were new worries. And when physical milestones had been met, there was an even longer wait to ascertain whether their child would have any verbal, mental or emotional delays or disabilities in consequence of their early

birth. There was therefore a lack of resolution and the state of anxiety and heightened vigilance was prolonged. The following excerpt captures the relentless ongoing nature of these worries:

> *"He failed his . . . new-born hearing tests. He had to have further tests for that. He had to have further tests for his eyes. So, it's all these things they were saying, he might not walk, he might not talk, he might not be able to see and he's failing these tests, and I'm just thinking okay my child's deaf, he's blind but then when he had the further test, he passed one ear, then he passed the next ear, then his eyes were okay, so then you start getting that hope back . . . but then you start thinking okay, so what's the next hurdle, so it's walking or will he talk . . .will he be okay?"* (Nicole, 17:17)

Beth had similar fears about her daughter's physical development.

> *"Half of me was like oh God. She's not sitting up yet, or she's not rolling or crawling but then my other part of my mind was well, we don't really know how old she is . . . I don't know if this was me trying to convince myself to take the pressure off, that because we don't really know how old she is I'm not going to worry about those milestones."* (Beth, 6:15)

Over and above this basic level of anxiety, it emerged from the interviews that the trauma of the overall experience had brought on a general worry and anxiety they didn't remember experiencing before. Existential therapy recognises this as ontological anxiety and a link can be drawn between the newly heightened anxiety and

participants' recent sharp realisation of the limitations of human existence. Facing the sudden trauma of early birth foregrounds the harsh reality that life is unpredictable and can quickly race beyond our control. Existential theory would refer to this phenomenon as thrownness as the mothers are suddenly thrown into a situation without any choice, and in which they are helpless. It became apparent that their preterm birth experience had irrevocably changed their perspective on life. It was also apparent to them how this changed perspective differentiated them from other mothers around them:

> *"Yeah, I just I felt I just felt really, really lucky, and really, really conscious of how close I came to like being a bereaved mother. I think in some ways my perspective on life is really altered and I just, it was weird because like on some levels I think I became serious about everything because you know being like this crazy life-changing experience. Then on other levels. I quite, I was just like yeah, let's just enjoy life. Let's relax. This is brilliant. Don't sweat the small stuff. Yeah. So I dunno, I do feel a bit, feel bit different too. I feel like I do feel that I still feel a bit different to other mums my age that I know that yeah."* (Heather, 12:2)

> *"I think I didn't realize. I do now really appreciate how sort of fragile like human life is and you know how anything could happen really. We were very lucky."* (Nicole, 17:29)

5.2.2 The isolation of limbo

When the babies were discharged from hospital, the mothers felt they belonged nowhere. They were grateful that they were not ill enough for hospital, but they also felt that they didn't fit into the straightforward postnatal category of new mum and baby. They felt as if they had fallen through the cracks, first in terms of medical support for their baby, but also in terms of social support from friends and family, and they found themselves feeling lonely and isolated. The one place they did find comfort and support was from other mothers of preterm babies, whom they had either met on the NICU, or whom they had found through support groups or the internet. This peer support stood out as an important source of comfort.

5.2.2.1 Fallen through the cracks

The data strongly suggests that all the mothers felt a need for guidance and support, both medically and emotionally. However, they all felt that there was no place for them in the system. With their babies well enough to go home, they no longer had the support of the hospital and medical staff, but the babies were also not well enough to fit into the general postnatal support system provided by health visitors. All the mothers reported feeling that health visitors and general medical staff knew very little about the needs of premature babies. Without access to specialist hospital-based services they felt lost, helpless and frustrated. They also feared for the safety of their babies. This comes across in the following excerpts from the data:

> *"Because you've been in hospital you've kind of fallen through the cracks, so the um, special care unit doesn't want to know you anymore, postnatal doesn't want to know you anymore. Because I was still ill as well."* (Vicky, 22)

"It's a big jump from all that full-time support, even when maybe you didn't really want it, to just kind of 'Good luck! We'll send the health visitor around next week.' So yeah, it was a bit kind of from everything to . . . it didn't feel like nothing . . . but, it was obviously a lot less . . . Yeah, there wasn't that kind of support at all and it's not what I was expecting either, but it was just it feels like a safety blanket taken away a bit really all of a sudden." (Pam, 16:27)

The mothers struggled to access advice and support and felt the system in place didn't match their baby's needs:

"Yeah, you sort of worry about it more and more and I did feel like there's a little bit of a lack of advice. I did approach our health visitors actually to help with that and mmm, I dunno. They were okay, but they didn't . . . They weren't making any concessions . . . regarding her prematurity or they were just sort of . . . 'she should act like a normal baby', and it was quite difficult." (Heather, 11:18)

"So there was just sort of, 'these are the guidelines and sticking to them and there was no flexibility to allow for the fact that he was premature. I felt like as soon as he was discharged from hospital, I just sort of felt like I was fighting health professionals. And it's really, you want to be able to try and enjoy your baby not always just fighting like doctors and health visitors and that kind of thing." (Nicole 2:23)

Two mothers described being offered continuing neonatal care after hospital discharge. These mothers reported feeling less isolated and more supported than those who did not receive ongoing support. This suggests that continued support after discharge can make a significant difference to a new mother's mental state. This highlights the importance of continuity of care; support from a familiar neonatal worker provided comfort and was an important element in the success of support.

> *"We had the neonatal nurse come to home once a week to see her and weigh her make sure she was okay, which is very comforting because you had somebody there you can talk to."* (Anita, 3:21)

The mothers found that the specialist medical support was very good overall, but that accessing this help was not always easy. All expressed a need for further NICU support after discharge but this was not available. A few mentioned that the NICU staff had given them permission to contact them if they needed to, but the mothers still seemed to feel apprehensive about how this contact would be received.

The mothers explained that the appointments scheduled for following up their baby's progress were good, but that the long wait between appointments was difficult to manage. When concerns arose that generated high anxiety and worry, they had to hold on to their questions and concerns until the next appointment. This was difficult for the mothers, who all expressed a need for GPs and health visitors to have more specialized training in premature babies' development in order to be able to address the kind of concerns likely to be raised by parents of premature babies. Sitting with the unknown is notoriously difficult to bear; acknowledging that these mothers will

inevitably endure long periods of waiting for clarity on their baby's progress confirms the importance of support during this time.

Every mother commented on the role of the health visitor. There was a sense that health visitors had no knowledge or experience of premature babies and were unable to provide any help or support for their baby. This provoked a marked frustration at the fact that despite so many resources being spent on them, the investment was futile since the health visitors lacked the knowledge or training necessary to support these mothers effectively. At a time when specialist support is so important, this failure was very difficult for the mothers to bear. The health visitors' interest in the babies and their journeys indicates real interest and perhaps eagerness to provide help and support; but they were unfortunately untrained for this role. All the mothers stressed the importance of health visitors receiving specialist training about premature babies and their development in order to be able to offer support, knowledge and reassurance:

> *"And then with the health visitor, the first thing she said was, I don't know what to do with premature babies (laugh) so that was really reassuring."* (Nicole, 1:12)

> *"Erm, the health visitors aren't, don't know anything about premmies."* (Vicky, 1:27)

Heather's reflections on what might have made a difference to the community-based support suggests that these mothers' experiences can yield useful guidance for change.

"It probably isn't really realistic to train every single health visitor on premature birth in every detail, but I think just within each team would be really good to have a nominated person who could be assigned to mums like me. I think that would be a good, possibly sort of workable thing to do." (Heather, 16:18)

"It wasn't a very integrated approach I think, or it wasn't a very specialised approach. It kind of really felt like, the health visitor didn't really understand what I was talking about a lot of the time. She was interested. She was very nice but didn't really understand what I meant." (Heather, 2:27)

The lack of specialised knowledge of the health visitors also reminded the mothers that their babies were different, and that they did not fit into the regular system set up for postnatal support. This realisation was painful for some of the mothers:

"I always felt a little bit funny going to the health visitor clinics . . . with lots of babies being undressed by their moms and dangled to be weighed and crawling around on the floor and they were obviously all very normal healthy babies and being surrounded by normal healthy babies, I found quite difficult because it was really obvious that my baby was a bit different. Um, you know, she just looked different." (Heather, 3:7)

"No, I think it was just making allowances. And so, you know, like when I have to go and see the health visitor for her weight checks, we have to do that every week and we had to go into the clinic earlier so that she was not in a waiting

room with all the other babies that could potentially, you know, give her a you know, where she could potentially catch a cold." (Beth, 14:4)

The mothers felt in many ways that there was no place for them or their babies in the system. They were grateful that their babies were not unwell enough to require special care, but they were equally aware that their babies were also not quite well enough to fall under the category of regular postnatal care. They all suggested that this gap could be closed by specialist training provided for health visitors. Mothers who received home visits from neonatal nurses from their unit felt considerably more supported and found this a useful and comforting service.

5.2.2.2 Feeling dismissed

When attending doctors' appointments, 3 of the mothers felt that they needed to beg for support in order to be heard. They felt that they were stereotyped as over-anxious mothers of premature babies and that their concerns were not taken seriously. For example, doctors seemed to brush off Vicky's concerns, dismissing them as anxiety, when in fact her son had an allergy to cow's milk which needed to be addressed. Nicole described having to fight over a number of years for doctors to acknowledge her concerns about her son's physical development, which was eventually diagnosed as a neurological disorder.

"But again, the paediatrician he was, um, I got called a hysterical mother once, I got told I was trying to medicalise my child . . . but I finally just did it and everything went away. And they went, "Oh, maybe he, maybe he has a dairy allergy." Yes, that's what I've been saying for about 13 months.

Something like that." (Vicky, 10:1)

"I mean when he was about 4 months old, I noticed that he wasn't moving one side of his body and that was just a fight to try and get him the support he needed. . . . He's got a developmental coordination disorder, but I had to fight for two years for people to just listen to me that there's something not right with my child and it's just . . . I don't . . . I think it's too easy to say you're a nervous first-time parent." (Nicole 3:9)

These experiences highlight the precarious feedback loop between trauma-driven ontological anxiety and the physical dangers related to premature birth. This study highlights the trauma involved in this experience and its far-reaching consequences. However, this theme highlights that focusing only on the fear and trauma can lead to overlooking some of individual, nuanced elements of this experience. In these two cases the doctors leapt to a diagnosis of trauma, which prevented them from attending to the mothers' grounded and accurate practical concerns. This deeper understanding illuminates all the layers of their experience and the importance of moving between them interchangeably to acquire an accurate sense of their journey.

5.2.2.3 Feeling completely alone

"I've been through something that was really awful and I kind of feel like I went through it alone, even though there's all these medical professionals, you know that they're just there to do their job, which is to basically keep you alive. and keep your child alive and I don't know, even if it had been somebody in NICU if you had like some kind of counsellor or something where you could just knock

on the door and say look can I have a word or . . . just go round when you were visiting, like are you okay? Or like just check up." (Nicole, 14:24)

Ultimately, the mothers felt alone in their experience. Some felt physically alone as being away from family they lacked a familial support system and some felt emotionally alone because although they were in a network of new mothers, they felt that the mothers of full-term babies could not relate to their journey. As portrayed above, there was also a sense of feeling medically alone.

"It did affect my mental health as well, and I ended up being quite ill with it all and had to have like counselling, and medication, and everything. And I just think, I just wonder sometimes, if I'd received better support if I wouldn't have had to get to that point, just sort of so low and desperate, um, so . . . but we'll never know, ha." (Nicole, 10:16)

"I think mostly the focus of me feeling bad was just feeling a bit isolated and like alone . . . like no one understands." (Heather, 12:21)

"You know nobody, once you get to the six-month stage, nobody actually possibly cares for you. Let alone asks you how you feel at all." (Pam, 12:8)

Some mothers reached a point where they felt it was no longer deemed appropriate to talk about their experience or their child's developmental challenges because others expected them to have moved on:

"I think there is a little bit of a taboo isn't there? That you're not supposed to kind of talk about it past a certain point . . . so you're always slightly behind, so everyone else thinks that you're kind of going on with, and onto the next stage, but you know you're still, still waiting." (Vicky, 5:3)

"Even now when I'm talking about it thinking I must sound like a real wet lettuce. I just think you really must be thinking, 'Oh God, get over yourself love'. I know. I mean, it just feels sort of weird speaking about it now even." (Pam, 13:1)

Beth did not describe feeling this same level of loneliness. This might be because she has two friends who have both had premature babies. She describes these friends having been a good support to her, as seen in the excerpt below. This strengthens the idea that support from others who are trained or knowledgeable about the premature birth experience can prove extremely valuable:

"And I thought well, I know this can be okay. I know this can be okay because my friends that have been through this, their babies are okay. So I think maybe that might sort of contribute to sort of my feelings during the NICU process. I have friends that have been through this and their babies are okay and those two friends did contact me as soon as they knew that I'd given birth early, and were there with their reassuring words and so I did have that support. That helped, that reassurance." (Beth, 12:4)

Eleanor too did not mention feeling the same level of isolation. Eleanor's experience suggests that community-based support was helpful in alleviating this sense of

isolation. This support seems particular to specific resources that had been set up in Eleanor's community. She speaks of meals and childcare support from friends and family. She also mentions how non-profit organisations provided lifts to the hospital and support for her older son during the hospital stay:

> *"I felt a little nervous about that but being in the Jewish community helped with that because with people around you didn't feel isolated. I felt that if I was nervous about something, I could talk to a friend so I was happy to have him home but, you know nervous about those things."* (Eleanor, 2:21)

Eleanor's experience of community support evoked a sense of loss within me. I come from a similar cultural background to Eleanor's, but it had never occurred to me to access community services as she did. Much like some of the other mothers, I felt that my baby was going to be okay and that there were probably others who needed support more than I did. Looking back, lifts to the hospital and extra meals could have made a considerable difference to our experience and I regret not reaching out for more practical support. Although I had found it easy and natural to reach out for emotional support, reflecting that seeking support in other areas had not even occurred to me gave me valuable insight into how easily some mothers could miss out on accessing essential help. This evoked in me a greater sense of empathy for their sense of isolation and highlights the importance of support being actively offered rather than expecting mothers to come forward themselves.

However, Eleanor recalled how this support reduced significantly after she brought her baby home:

> "*Then I came home, and I feel like it wasn't the same because I think people think 'a baby in hospital' and like really step up, you know. But then it's different when you're home. People are aware and you know asking a lot and um, food,*

I think there's a lot of offers of food and I feel we are in this, you know, community, and people care and I did not, we did not have that much support from family." (Eleanor, 9:2)

However, despite much social support, like others, Eleanor felt an attachment to the hospital staff and appreciation for their support. She too felt there should be more continuity:

"there's a feeling of a little bit more continuity with the hospital, maybe some of the nurses to have more of a connection . . . there's a little bit of a missing piece that I feel could have been filled in." [Eleanor, 10:22].

5.2.2.4 Feeling different

For some mothers, this feeling of isolation manifested as feeling other than, or different from, other mothers and babies around them. Although most of the mothers describe making efforts to join group activities such as NCT groups, music groups, or baby massage groups, there is a common thread of feeling different from the group. 3 of the mothers describe being aware that their baby looked different from the other babies and felt that this would be noticeable to other mothers in the room. In other cases, mothers felt that the discrepancy in developmental progress between the premature baby and the others would be very noticeable and this made them feel uncomfortable.

All the mothers talked about the natural urge to compare their babies to others of the same age. They described this comparison as painful but unavoidable. They wanted to measure their baby's development against that of other, full-term babies, at the

same time knowing that this was not a fair comparison. Despite knowing this, the comparison created anxiety in all of them. This may have added to the feeling of being set apart from the group and feeling alone:

> *"Yeah, it's yeah, it was say, going into normal healthcare environments with a baby that had been sick and sort of had the appearance of a baby that obviously had different experiences was quite hard."* (Heather, 4:8)

Pam and Anita knew they were making invalid comparisons but this did not prevent them from doing so or worrying about it.

> *"So normally, I'm quite a competitive person and I know some mums can be quite competitive, but I have not been competitive at all about my boy because I just knew he was going to do everything later and slower and until he got to the point where he caught up physically and mentally." (*Pam, 15:4)

> *"Whereas all the other babies the same age are moving about or, you know, showing signs of interacting with you, they don't do it because it's not their age to do it and you know that, but at the same time you're always conscious. It makes you more worried. What if? What if? What if? And she did everything at the right time and at the right stage. She was doing everything properly. But then again you have comparisons with other children. It naturally happens . . . You know that you mustn't compare but you do it naturally without realizing."* (Anita, 3:11)

This feeling of failing to fit in emerged many times and in different ways, despite the mothers being in group situations with others. This could indicate that despite being a part of a group, the uniqueness of the premature experience makes these mothers feel unable to integrate into the mainstream mother-and-baby environment. It indicates a need for a space for these mothers to express and share their experience with others who can receive and empathize with their experience in a non-judgmental way.

Eleanor spoke from a different perspective. She was so happy that her son was alive, well and home with them, that she found she had far fewer expectations of him than she had had of her older son. For her there was no comparing in terms of expectations but rather a simple happiness that he was there with them. At first this could be perceived as different from the tiger-mother response, but on reflection, it appears that this could be another aspect of tiger-mothering, in which a basic level of survival is the main focus and goal.

> *"It was like 'you don't have to be anything!' Like I'm just so happy he's here like, you know, I don't care if you like, you know if he's not a genius or you know? I felt like I was more demanding of my other child like he's gonna be brilliant and he's gonna be so intellectual. I just have all these like silly thoughts like that aren't important. With this it's like, he's well, he's here, he's cute. Yay!"* (Eleanor, 7:28)

Eleanor's perspective strongly impressed me. I am all too familiar with the high expectations set for our children by parents and society. It is so easy to get caught up in those standards and judgements, which can distract from the miracle of a healthy

child. Eleanor's words have stuck with me and I have tried to make this a mantra in my home, remembering to delight in the tremendous blessing of my healthy children. I was able to share the existential gratitude expressed by all my participants.

5.2.2.5 Perceptions of the baby

Throughout the narrative there are references to how the baby was perceived by others. This topic can be divided into how, during the first year, the mother perceived her own baby and how she believes others perceived the baby. On reflection it can be understood that both aspects affected the mothers' emotional response. The onlooker's perception was meaningful to the mothers and was sometimes received as potential judgement of their ability as a good or bad mother.

> *Um, and he also . . . sort of emotionally and mentally he did have the delay, um, so, people see this, you know . . . Um so you know he looks, he looked, and of course he is physically able, so everyone assumes that he's the age, slightly older. . . . Um, so we had a little bit of, you, I felt I had to defend (laugh) him on that one . . ."* (Vicky, 19:20)

> *"It didn't make me feel less proud of her but it did just sort of bring this emotion that I had never experienced before which was like kind of feeling really defensive of her and feeling like don't criticize her because she's brilliant and amazing."* (Heather, 4:3)

Vicky and Heather's defensiveness about their baby is powerfully expressed, as is that of Eleanor and Beth:

> *"He was just our baby - like he was fine. And um, I think I have, I'm a little more protective of him or something like he's a bit, maybe he's a bit delicate or something."* (Eleanor, 6:28)

> *"So it was always always on my mind that she has two ages and when people would meet us and go goodness your baby is tiny how old is she? And I've always felt that I had to sort of explain her size. 'Oh, well, she's this old actually'*." (Beth, 6:9)

In different respects, throughout the narratives the mothers made comments that give us an understanding of how they perceived their babies. Through the lens of comparison, as noted above, the mothers saw their babies as different or odd and were sure that everyone else could see how different their babies looked. The baby's physical appearance often did not reflect his/her actual age. This was something that played on the mothers' minds, triggering a defensive impulse to defend their baby or their baby's behaviour to others.

The words 'fragile', 'tiny' and 'delicate' were frequently repeated, indicating how the mothers felt that their babies were vulnerable and susceptible to illness and harm. As discussed above, this reflects a realistic and scientifically endorsed concern; however, this vigilance and fear had possibly seeped into other aspects of these mothers' perception of their children and mothering style.

“Tiny” (Nicole, 13:1)

“Tiny” (Pam, 10:12)

“Tiny” (Beth, 6:11)

“Tiny” (Anita, 10:2)

“Fragile, delicate” (Angela, 8:21)

“Delicate” (Eleanor, 6:30)

Some mothers referred to more recent experiences, now that their child is older, sharing the feeling that they will always be ‘a premature child’ and that this will always be part of the way they view their children.

> *“The only other thing I suppose is that my daughter will always be a premature baby and I don't know if I'll ever stop thinking of her like that and stop labelling her. That, I suppose that's something well, it's with me and it's with her and it's you know, for the rest of our lives, but I'm still conscious of it.” (*Beth, 17:19)

This indicates that the mother’s perception of her baby is created from a much broader picture of the whole birth experience and journey. She is looking at both the baby in front of her and all the baby has gone through to reach that point. Just as she can view her own experiences out of the context of the NICU, she cannot view her child out of the context of prematurity. This suggests that the premature birth journey contributes to the meaning of her relationship with her child and is part of the essence of the mother-baby bond, her perception of her child, and perhaps even her perception of herself as a mother.

5.2.2.6 The importance of peer support

As with the need to stay connected to the NICU, all the mothers expressed a sense of particularly useful comfort and support from other mothers who had been through the same or a similar experience. A common feeling seems to be that one can only understand the experience if one has experienced it. This may have some connection to the fact that prematurity can be described as a liminal experience. A premature baby does not completely fit into the category of a ‘sick’ baby, but neither can it be classified as a well, full-term baby. Inhabiting this grey area of experience perhaps makes the experience hard to define and the feelings and emotions difficult to accurately describe.

This exemplifies the challenges of an interpretative phenomenological approach. The mothers expressed the impossibility of putting their experience into words that would do it justice. They felt, therefore, that it would be impossible for another to truly understand it. Yet I was attempting to do just that. I respect that I can only understand their journey through my interpretation of their descriptions, but by attending to their message that the true extent of their trauma cannot be verbalised, I could hold onto that depth and portray that truth in my findings. In the role of researcher I approached their interviews with an open mind. I was not reflecting on my own experience but was wholly focused on absorbing theirs. However, having been through this experience myself, I am also in reality a ‘peer’. I could not change the fact that I was listening to their story with a basic understanding of what they had been through and this allowed me to understand their narrative more empathetically and accurately.

7 mothers spoke of the comfort and support they got from other mothers of premature babies. The source of these relationships were different: Anita, Heather and Vicky kept in contact with mothers they had met during their NICU stay; Pam, Beth and Eleanor have friends who have also had premature babies; Vicky and Anita also befriended mothers of premature babies they had met at mother and-baby groups and Vicky joined a local support group for mothers of premature babies. Vicky also actively pursued online forums and chat groups for mothers of premature babies, which she found to be an invaluable support.

> *"We've become each other's friends and it's nice because we all, we supported each other at the time in the hospital. So we just, we just get it on a . . . we know that each other gets it and we all remember the details of what each other went through and so yeah, it's that's one way in which I gained support as well."* (Heather, 9:12)

> *"My initial mom friends are the NICU friends. So . . . and we're all immensely proud of our children and each other's children, and what they've achieved, and their milestones and I suppose it was good to have that support because our babies were meeting milestones and we were recognizing them and not judging on if they were early or late."*(Beth, 17:9)

While Beth and Heather leaned heavily on their NICU peers, Anita and Pam found similar support in mother-and-baby groups later in the journey.

"It's almost a support network. I've still got a friend from there I catch up with regularly and there was one of the other mums in there; she had had 2 premature babies before them. So you could talk to them. The lady who ran the group had a premature baby and then she was just, "Oh, it's fine. See lots of babies just do this" . . . and then my anxiety diminished a little and I started feeling like 'hang on, why am I so stressed about it?'" (Anita, 14:22)

"Yeah, so it was nice. It's nice, you know talking to people that have been through it as well and they were even though you feel like sometimes you're talking like an insane person, there's someone else but that is the same, or feels the same, has been through the same things." (Pam, 8:9)

The need to be heard and to share and normalize their experiences is evident in these quotations and the role of peer support can be clearly identified in fulfilling these needs. Peer support was also an opportunity for information sharing on weaning, accessing medical support and reaching developmental milestones. Consulting with other premature mothers gave them an opportunity for reassurance and encouragement that they were doing the right thing and helped them to learn to become a mother.

"Mumsnet is great. We had a running midnight thread. So while I, we used to chat while we fed in the middle of the night, which was great. Um, and then we had another one as well. And on both of them . . . you know, you'd sort of slink onto the thread, and guilty, saying I really feel like screaming at him tonight cos this is just too much. And they all go yeah, it's part of being a mother, you want to scream every so often, you didn't, its fine, so." (Vicky, 25:33)

“So you could compare the 4-month-old to baby, the actual 4-month-old. And actually yeah, that's what she's doing now that looks normal or they give you suggestions on oh, have you tried this, you know, if you want to do baby- led weaning try yoghurt. Try this or try this.” (Anita, 14:18)

5.2.3 Attachment to the NICU

Understanding how the mothers felt different in mainstream groups may provide some background on the next theme. Common feelings of a strong attachment to the NICU post discharge emerged as an unexpected but strong theme. All the mothers spontaneously shared their longing to remain in touch with the staff on the NICU where their baby had been hospitalised. This longing could be grouped into 3 main categories: needing guidance and support; acknowledgment of the trauma, and gratitude towards to the staff.

5.2.3.1 Needing guidance and support

The first relates to the guidance and support needed during the weeks and months following homecoming. The mothers all felt that the only source of information that truly understood the needs of their baby was the specialist neonatal staff. When they had questions or concerns, they knew that the neonatal staff would be able to assist or reassure them, as they had done during the first weeks on the unit. Perhaps the restricted access to this support also strengthened the wish for connection:

“What would have been good would have been someone from the NICU coming to our house, maybe a, like a specialist in the first few months, like a specialist premature baby team coming to the house.” (Angela, 15:25)

“Oh I just I wanted to be a little more in touch. Anything. To feel like everything's fine. You know, maybe it was like. . . You know, I didn't. Forget what it should have been. Just in terms of what I wanted; a little bit more like maybe calling to check in kind of. I felt like I was so attached to that place and then I'm feeling like I would call, I almost wanted to call them and be like ‘hi, we’re here, like we're home’, you know . . . a little more of some contact, you know with the hospital.” (Eleanor, 10:12)

5.2.3.2 Acknowledgment of the trauma

The second category seems to cover the idea that neonatal staff are the only people who had borne witness to the mothers’ experiences. They are the people who know exactly how the journey of the premature baby unfolds. They know the dangers, the frightening pitfalls, and fears that loom over even the smoothest of premature developmental phases. The mothers are strongly drawn back to these people, who can understand their experience without the need for any explanation. They are also the people who had encouraged their mothering skills and given them reassurance and confidence in their ability to care for their baby when no one else could. This seems a powerful connection from which separation is painful:

“You know this is someone who looked after you in your hour of need kind of thing and it's nice for her to meet them and for them to see her but, I don’t know, I appreciate it's probably not a realistic idea.” (Heather, 18:16)

"I think we sent pictures at one point or um, you know, there's a feeling of wanting a little bit more continuity with the hospital, maybe some of the nurses to have more of a connection. I think I would have liked that because you do get to know people there and some people maintain those connections, I know, very strongly, and they go back all the time and I thought we would do that." (Eleanor, 10:22)

The sense of experience shared with the NICU staff through the journey is apparent in Anita's thoughts:

"You just kind of sit there thinking, it's their job to do it every day. Yes, but it's those little things that make a difference. They almost formed their attachment with the child themselves. At the beginning they see the personality of the baby before you can." (Anita, 12:4)

5.2.3.3 Gratitude and acknowledgement

The third category is that of gratitude and acknowledgement. All mothers spoke about wanting to take their growing healthy children back to the nurses and doctors who had taken care of them and nursed them to survival. There is a strong wish to show gratitude to the staff for their care and expertise, and to show that the mothers had not forgotten their appreciation. 2 mothers also felt it important that their child should see the people who had cared for them and feel appreciation for this. The immense gratitude of the mothers for the staff is apparent, as is their sense that this service is

important, and that these people are an integral part of the story of the survival of their baby.

> *"I think it would be nice, like we occasionally make contact with her old doctors like just sending emails or 'Happy Christmas; here's our daughter. Thanks for everything.' And sometimes when we've gone for follow-up appointments, we popped by the neonatal unit just to say hi."* (Heather, 17:26)

> *"When we were in NICU we had an amazing team of staff. You know, all the nurses and the doctors were fantastic and I'm still friends with some of them now so I can't fault the way they were with my son when he was in hospital."* (Pam, 15:17)

The strong attachment to the NICU also indicated the mothers' sense of belonging. While they felt that no one else could empathise with their journey and found it hard to relate to friends and family, the NICU was a place that understood their experiences without need for explanation. The NICU was at first a strange new environment to navigate, but by the time they left it had become their new normal – a normal they quickly learned had no equivalent in the outside world. They longed to return and experience again that sense of comfort, belonging and safety, yet at the same time they were grateful to be moving on their journey back to normality.

5.2.4 Feeling like a mother came later

Most mothers shared feelings of shock and disbelief at the thought of being a mother. They described a sense of mothering on autopilot; being able to go through the practical motions of taking care of the baby but without feeling an emotional connection. They found that their emotional connection grew slowly over time and that this seemed to develop in parallel to their baby growing, developing and becoming more robust. There seemed to be a connection between feeling like a mother and feelings of guilt related to their failure to carry the baby to term, thereby contributing to their baby's suffering.

5.2.4.1 A shock transition

In most cases early labour happens suddenly and unexpectedly. The participants had not yet mentally prepared themselves to meet their baby. They remember being in shock and disbelief at seeing their baby for the first time. They felt unable to identify as the mother of the baby they were looking at:

> *"I'm sure for any mum of the preemie baby, having them whisked away as soon as they're born like has massive effect. I think I got to hold him for a couple of seconds, if that, and he was whisked away and I made my husband follow him, to make sure it was like the right baby in the right place. But still I remember when we were taken to see him. Like my first reaction was wow, he's amazing. He's so gorgeous. Where's his mum and dad? Uh, is that me? Like that, you know because I, it was such a surprise that he came two months early. It was such a surprise. I hadn't even read the chapters in the book about birth. I had no idea about anything and suddenly there was this baby and I just wasn't ready."* (Angela, 4:24)

Angela's honest and vivid account depicts the whirlwind launch into motherhood and the sudden bewilderment of having a baby. The inability to connect emotionally is also powerfully expressed. Beth's experience is similar in many ways:

> *"Just this sort of like looking at a baby in an incubator and I felt no recognition. I don't know what I was expecting to see but I was like, 'Oh my God, I don't recognise you.' You're not, you don't look like how I imagined you'd look. Even though I hadn't imagined how you would look . . . you don't look like mine. And I think it I just felt it was like looking at a stranger but a stranger that was very much a part of me, that had come from me. So it's quite an unusual feeling and experience."* (Beth, 10:21)

These accounts describe only the beginning of the mothering identity but Beth's comments below show how making sense of being a mother was an ongoing, complex process involving different constituents including bonding and emotional response.

> *"I think as well there was the bonding element . . . that goes hand-in-hand with that sort of the birth and holding your child . . . so . . . I feel like . . . sort of going into motherhood and feeling like a mum was sort of a delayed process almost, and you know, I feel really an incredible bond with my daughter now, and I definitely feel like a mum, but I think it took a while for me to sort of sort of develop those feelings and emotions."* (Beth, 8:4)

These comments indicate that the mothers were in a state of shock which perhaps added to their inability to feel emotion to their babies. They had not had a chance to

mentally prepare or emotionally make their transition into motherhood. As the quotes show, the mothers question why they were unable to feel for their babies as they had expected they would. Some attributed this to early birth and the loss of the unique experience of skin-to-skin contact directly after birth. We will also see in later themes that connecting to the baby under such precarious circumstances was also a very frightening prospect.

5.2.4.2 Mothering on autopilot

When participants described caring for their babies in the early days and weeks after discharge, they seemed to recall a shift into an automatic mode that seemed to remain disconnected from emotion. They describe having felt able to follow the necessary procedures to care for their baby, but that it felt like following instructions by rote rather than a spontaneous expression of love for their baby:

> *"Um yeah, I remember, I've never had any difficulty in thinking about the sort of things that you tend to do to keep him alive. I always thought that that was kind of my job in a way. Was kind of, except that I . . . it felt like acting the role I think, sort of, fake it till you make it, yes?"* (Vicky, 14:4)

> *"But really like I don't think there's anything easy about it. It was just, you just, you just do it. I think it's like you're almost just going through the motions just to reach that basic level of survival."* (Nicole, 20:21)

Angela and Beth also experienced a very practically focused relationship in the early months, but on reflection both question whether they had perhaps submerged their emotions under this practical routine.

> *"I think something about that gung-ho feeling of we're fine. He's fine. He doesn't need me to like fuss over him meant that, I dunno, I think I was quite maybe functional in the way I looked after him. I think I did quite a lot of talking and smiling and singing and all the things you're supposed to do. But looking back I . . . I don't think I quite had that sort of a really tender way of looking after him that I think probably does benefit babies."* (Angela, 14:6)

> *"I think I just, you just, get on with it, and go through the motions . . . I think now as the time has gone by, I realize that her prematurity did affect me. At the time I didn't think it had."* (Beth, 2:32)

Anita gives further insight into this response, suggesting that avoiding an emotional response allows the mother to function and care for the baby. Her view implies that although emotional engagement may have added to the mother-baby relationship, it might also have been so painful and traumatic that it could have left the mother unable to cope or care for the baby at all.

> *"Mentally you know it's normal but emotionally it affects you and then if it affects you too much, you can't take care of the child. And I think my parents found it really hard that I was so . . . I think my husband did too because they thought I was totally unemotional and I dealt with it too clinically, so you feel like you kind*

of just focus on the practical and make sure that all the practice of my physical needs were met rather than yes, seeing it from emotional." (Anita, 10:26)

Pam was of a very similar opinion, and here the disconnection became apparent through the long pauses in her utterances; it was as if she were talking about her memories from a great distance:

"You don't really think about what's going on because that might be a bit too scary to think about so you just kind of . . . (long pause) I think I was just on automatic pilot probably for the first three months after he was born really. Until we kind of got into a routine and I started getting less worried about that something might happen to him or whatever." (Pam, 1:25)

The discussion seemed to prompt participants to reflect on this response. Some questioned whether the medical environment of the hospital had perhaps made the care regime seem more medicalised and structured. There was also the element of being supervised by hospital staff, creating a feeling of being assessed on their task which perhaps disturbed the natural development of caregiving:

"When he did come home, I don't . . . I was . . . so I was like I may have been tired, we were tired, but I was completely, you know able to hold him and you know comfort him if I needed to. I could be a mother, like kind of make decisions or even not hold him. Like you could say you decided this is a time to let him cry for a minute . . . I could decide that but if he's there and he's like he's a new

baby. I wanna hold him. He's crying. Like it felt terrible, you know. So that, I didn't have that issue when he was at home." (Eleanor, 6:17)

"It's just obviously when you're not there you lose all that amazing, wonderful support that you had basically, you know. Although it was lovely leaving the hospital and not feeling like you were being watched all the time how you are with your child. So in one respect that was lovely to have private time with your child and you know, not think aw, am I holding him okay because that nurse is looking at me, you know . . . It's a big jump from all that full-time support, even when maybe you didn't really want it." (Pam, 16:19)

Others thought that perhaps the fear of the babies' fragility and the lingering fear of potential loss made it difficult for them to allow themselves to connect emotionally to their babies. The need to engage practically with the baby was immediate and had serious consequences. The mothers therefore engaged with this care, whether they felt ready to or not. However, engaging with the baby emotionally had fewer immediate consequences and could therefore take the necessary time to develop. Over and above this, an emotional connection would not be possible to engage by rote:

"He's like my best friend now and like, I absolutely love him, but for the first . . . you would say it was just, I don't want to say a chore, but it was almost like he was just a chore I'd have to do because it was just so . . . this like overwhelming responsibility and I just couldn't really connect with him as like another, you know person. I feel really awful saying that." (Nicole, 15:23)

The primal instinctive mothering mode continued in the months following hospital discharge. It seems it was only when milestones were reached and normal development began to become apparent that the mothers felt safe enough to interact with their babies more emotionally:

> *"And after she was one, even up to 2, it was almost like there's a marked difference in how I react with my daughter."* (Anita, 15:20)

> *"I think that's why it hit later because you know in the first few months it was literally, I was, I guess I was just, so worried . . . and I suppose when he was putting on weight nicely and I guess when it got to like the six-month stage he sort of, we were a bit more relaxed about it . . . I suppose that's when the other things started creeping in."* (Pam, 10:4)

The emotional distance is evident in these quotations. The autopilot mode seems a form of self-preservation, enabling mothers to keep a distance from the intensity of the situation in order to keep going and fulfil their parental responsibility. This evidences a high level of resilience in these mothers and perhaps indicates why medical staff and family members experience them as coping and not in need of support. However, it also indicates the trauma and fear experienced by these mothers during the first year after hospital discharge.

5.2.4.3 Feelings of guilt and failure

When exploring how their feelings of being a mother developed and how they bonded with their baby, 4 participants shared how the development of their mothering identity

had been affected by feelings of guilt and failure. For Nicole and Anita, the guilt related to giving birth early and putting their baby into this position; and Beth and Angela felt guilt about their lack of emotion for their baby when they first saw them. The quotations below illustrate how Nicole felt that by giving birth early she had failed her child and failed in her role as a woman and a mother. These feelings were clearly balanced with a reasonable understanding that Nicole was not personally responsible for the early birth and could not have done anything to prevent it. However, the internal conflict and sense of guilt is apparent, as is the difficulty in letting go of these feelings of responsibility:

> *". . . a sense of feeling like I didn't deserve to be his mum, because I felt like I was the one who put him in that position so there was this overwhelming sense of guilt for me as well, um you know, like I failed him, my body failed him, and I didn't do, the one job which I think as a woman, that is something a woman can do. Men can't do it. Nobody else can really do that. It's like that's your job for your child, and to have failed at that, with no reason. I sort felt like I failed to protect him then, so I've had this duty to protect him now, but I didn't think I deserved to have him as well."* (Nicole, 16:16)

> *"I imagined in my mind. I would you know, see this baby or you have this baby and hold this baby and just feel this overwhelming love and . . . and I didn't have those feelings, um . . . so think a part of me is surprised and a little bit shocked and then with that comes, yeah, I kind of feel a bit guilty to her for not feeling anything. "(*Beth, 10:11)

> *“And then you just feel guilty. It's my fault she came early. You know, what if she hadn't come early, she would be fine. You go through those transitions when you know, it's not your fault and I was high risk.”* (Anita, 10:22)

Vicky mentioned feelings of failure but related to breastfeeding. Her failure to breastfeed her son left her feeling a complete failure. She links this to a lack of guidance and support, which connects to aforementioned themes of isolation and the need for support and guidance.

> *“I felt, completely erm, sort of completely lost really. I mean the whole breast-feeding thing was really big actually for me, I sort of, that felt like a total failure. Took me quite a while to get over that one, that I only made it, mixed feeding to 4 months.”* (Vicky, 7:29)

The other 4 mothers did not mention feelings of guilt or failure related to birth or bonding. However, these vivid accounts give a rich insight into how some mothers feel personally responsible for giving birth early and into many of the difficulties this entails. The above quotations indicate how complex responses to notions of responsibility, duty and guilt can impact on the process of feeling like a mother. As mentioned above, taking responsibility for occurrences that in reality are beyond our control can sometimes serve to provide a false sense of control and security in a time of fear and upheaval despite the painful guilt and responsibility being difficult to bear. This poses a possibly fruitful perspective to consider in the context of an existential crisis.

5.2.5 Bonding in the shadow of the threat of loss

All participants confided that they did feel a bond with their baby but that it was different from what they had expected to feel. It was described as an instinctive or 'tiger mother' type of bond, focused on the baby's progress and a desperate will for them to survive. They shared that their emotional bond grew and developed as their baby grew and developed. This also seemed to develop as their fear of loss slowly began to reduce in the later months. Reciprocity played an important role in the onset of bonding and when the babies began to smile and interact, the mothers felt a shift to a more emotional relationship.

Facing the precarious outcomes of an early birth thrusts the mother into a crude confrontation with the reality of human mortality, death and loss. Moreover, this experience is drawn out, as the mother watches a baby fighting for survival in the neonatal unit, while the outcome remains unknown. These mothers had to engage with these potential outcomes as part of their daily reality. This stripped away their fantasy that everything was going to be okay in the end. It is understandable therefore that when these babies were discharged from hospital, the mothers' perspective could not be suddenly reversed. The data shows that this can affect a mother's ability to bond with her baby:

> *"I saw him for the first time and then you can't, I couldn't hold him for another like few days until he came off the ventilator. So there's just no chance of that connection and that kind of thing . . . I think also you don't really want to bond with them just in case something goes wrong, because you don't want to be*

hurt if you do lose them. So it's a protective measure as well as like, a sense of responsibility." (Nicole, 16:8)

"What's the definition of bonding with a baby? Because you know, I would have fought anyone tooth and nail to keep him, and keep him alive, from birth. I'm still not sure . . . so, yes . . . I don't know." (Vicky, 25:4)

Slow movement towards healing and bonding occurred, but other anxieties remained and the threat of loss still loomed. In most cases either emotional, verbal or physical development were delayed, and these were ongoing worries for the mothers, who wondered what their baby's emotional, intellectual and physical capability would be like. This loss was not related to the potential physical loss of the baby, but it threatened the loss of their expectations of a well-adjusted, healthy, able child:

"That one worried me for a very long time, uh, at the 2 year review, um, you know they give you that little list of all the things they were supposed to do, and the physical things tick, all the way, and then you get to the emotional bit and talking and all the rest of it and it's like, none of it." (Vicky, 22:21)

"So now I can start to have hope again for his future. But that first year I would say is just all like the child in your mind has died and you just have to see what happens. You can't hope." (Nicole, 17:26)

These accounts show that after facing the reality of possibly losing a baby, this intense fear and pain is difficult to fully recover from. Although the immediate danger has

passed, the possibility of that reality has become realised for these mothers and this remains part of the new way they interact with the world and with their babies:

> *"I mean certainly, it's interesting, my husband still, has to go check he's breathing at night. I don't quite so much . . ." (*Vicky, 12:29)

> *"Of course, babies will walk and talk. you never think that your child won't be able to do all these things . . . It's not something that you really think you could end up being in that kind of worlds and it's just, it's a terrifying thing."* (Nicole, 19:6)

Bonding experiences were not identical for all 8 mothers. This perhaps validates the authenticity of this research, as no two mothers' experience of bonding can be genuinely described as the same. Vicky felt that she did not bond well with her son until after his first birthday but conscious of her love for him now, she questions what 'bonding' really means. This suggests that bonding may not be as one-dimensional or rigidly defined as we might assume. Angela felt that it took her a long time to bond with her son and believes she may still struggle to bond, soothe and comfort him in the way she thought she might:

> *"I'm not sure I did bond particularly in the first year. It was always sort of . . . I don't think he would know that though. Um, I don't know, what's the definition anyway? I, it's, 'cos this one I've thought about a lot,' cos I have been upset with people of course."* (Vicky, 24:32)

“But like I did grow to love him (laugh) thankfully . . . yeah, there definitely wasn't that instant bond . . . and that's like made a lot of difference. Yeah, and I'm sure it wasn't just the initial bonding thing though. So yeah, all of these developmental things like not getting that smile really early on and being a baby who, he was very uncomfortable and needed a lot of um, just like a very upset and uncomfortable baby. It sounds terrible to say but it's harder to love a baby who is sad all the time than a baby who smiles at you and is just a delight. But, I guess the more that they can communicate with you and interact with you the easier it gets.” (Angela, 5:11)

5.2.5.1 A different kind of bond

The other mothers described bonding with their babies, but all said that they did not bond in the way that they had expected to or as they imagined others might bond with a full-term baby that had enjoyed an uncomplicated birth. It seems they each had an expectation of what a mother should feel like and that their actual experience did not match up to these expectations:

“But I’ve kind of wondered whether I had slightly um, rose- coloured expectations in the first place, and whether I just didn’t meet my own slightly uh, over-the-top expectations of what mothers are supposed to feel for this baby in the first year of life.” (Vicky, 25:16)

“I remember I could hear in the next labour room to me this woman screaming ‘my baby! I love you my baby!’ It was like, ‘is that how you're supposed to feel’? (Laugh). ‘Cos like I didn’t feel like that at all.” (Angela, 5:8)

These comments suggest that there were expectations not only of how they would feel as mothers, but also of the imagined child and how they would relate to it.

> *"And maybe there's an element of shock associated with that because through pregnancy when imagining motherhood and becoming a mother you know, I imagined in my mind I would see this baby or have this baby and hold this baby and just feel this overwhelming love and . . . .And I didn't have those . . . .feelings, um . . . . So think a part of me is surprised and a little bit shocked."* (Beth, 10:10)

> *"Even though the child in your head is not a real child, but it's that like expectation and your hopes and dreams for them."* (Nicole, 17:12)

Yet, Heather, Pam and Eleanor did not feel that difficult circumstances had affected the bonding with their baby and described having bonded well or adequately:

> *"I feel like it's actually worked out okay, and I'll never know, you know, what the alternative would have been. If she'd been put on my chest as a healthy baby and I had never been parted from her, I won't know what our bond would have been like in that situation but as far as I can tell the bond is ok . . . So yeah, I feel like physical separation was sort of compensated for by just pure, you know desperation and love towards her and it all worked out all right in the end."* (Heather, 16:1)

“I never felt I didn't have that bond with my son. I always felt that, I always thought it was there. Um, so no, I don't think it affected the way I would have been a mum. I mean, I know it's hard to say, I don't think so. I don't feel like it.” (Pam, 10:25)

“My connection? It's hard, but I guess if I look at it, it goes nicely. Like looking at each other um . . . smiling. Um, it felt like a good nice simp . . . not complicated connection and felt like I could look at him and enjoy him and if he . . . it’s weird, sometimes I think about this, because it was not like ‘he's premature and so there's all this trauma and complex feelings around him because of that’.” (Eleanor, 7:15)

5.2.5.2 The tiger mother bond

Angela described a sense of fierce, visceral, almost savage protectiveness:

“I remember very early on like I had this thing, like really like a . . . tiger mother. Like, I dunno, pride when he started feeding on his own, um, and like encouraging him was really visceral. But I don’t think that's the same as a bond or maybe it’s a kind of bond, that’s not the same as the kind of loving bond. I didn't know if it was more of a like a drive for him to do well and develop and succeed.” (Angela, 6:1)

The expression ‘tiger mother’ is particularly striking as it evokes an image of the intense and fierce protection of a helpless cub, but even more poignantly, it evokes a

sense of impending danger and vulnerability in the unpredictable surroundings of the wild. This captures the sense of hypervigilance experienced in the aftermath of the trauma of premature birth, and the heavy sense of responsibility and duty to protect the vulnerable baby. It is a poetic depiction of being reduced to a basic survival instinct and fighting for the survival of the baby.

Some of the other mothers also described an automatic primal, instinctive bond that was fixated on the baby's survival. Getting the baby to survive engrossed the mothers and ignited a kind of force within them to do everything in their power to protect and rear their child. This intense feeling of encouragement and connection can be described as a bond and the mothers seem sure that this is what it was. However, they all felt that it was different from the kind of bond they had expected to feel, which they imagined to be less proactive and more relaxed and loving. The excerpts below give a beautiful account of these mothers' unique, intense bond with their babies:

> *"I didn't really bond with him like in the typical way . . . I think I just had this like overwhelming sense of responsibility because I was just so terrified that something bad would happen that that kind of took away any chance to really enjoy him. And because . . . I needed to make sure that he was alive and he was being fed and it was just sort of there was no real chance for me to enjoy him."* (Nicole, 15:15)

> *"I didn't see her for 48 hours after she was born because I was so unwell . . . But as soon as they took that IV out of me and I was allowed to move out of bed I went upstairs. I walked up to the NICU despite the midwife saying I should*

take a wheelchair. I didn't want to wait for anyone to go and see her. I wanted to see her, make sure she was okay . . . I had to have a wheelchair bring me back down and I had to sleep for two hours." (Anita, 11:4)

The quotation below describes Eleanor's memory of her strongest feeling of bonding with her baby. She describes this as different from what she had expected simply because it was her first encounter with a premature baby in an incubator. Unlike the other participants, this was Eleanor's second child and she therefore had had a previous full-term birth to which she could compare this different experience. She describes an instinctive need to comfort her baby:

"The most upsetting to me, traumatic for me which tells me something about being a mother was when we were in the hospital . . . And I was there watching him and he was crying and it was a point where I couldn't touch him . . . That was the most traumatic for me. And that's the part that makes me cry when I think about it and I think as a mother you just comfort your baby . . . and that to me was a lesson or I learned something about myself that . . . I want to be able to comfort my child. And so . . . as a mother you're just very aware like that's a deep need and it's interesting because I don't remember ever thinking that about my first child because I was always able to comfort him." (Eleanor, 5:17)

Eleanor's repetition of the word 'desperation' is also noteworthy. Although an emotional and loving bond was yet to develop, this word evidences an intense anxiety

and a maternal instinct to protect the baby. ‘Desperation’ may also evoke a physical need perhaps embodied in the experience of pregnancy and birthing a child.

5.2.5.3 The importance of reciprocity

The interviews reveal an apparent connection between bonding and reciprocity in the mother-baby relationship. 3 participants spoke about experiencing the first few weeks of mothering as a one-way relationship. They felt that they were putting in ongoing effort and care into this little baby, but without receiving any benefit in return. They explained that although the mother of a full-term baby carries out the same duties, she might receive cuddles from her new-born and perhaps a mutual satisfaction in breastfeeding, though this perhaps betrays a lack of understanding of the ability of even a healthy new-born to display active reciprocity; even smiling doesn’t begin before six weeks. But the mother of a very premature baby is unable to hold or cuddle her baby for many weeks and can feel that she does not get the same physical reward. All mothers described breastfeeding as a difficult and labour-intensive task; none of the care processes were referred to as mutually satisfying:

> *“I absolutely with clarity remember the first time he smiled at me properly. He was about 4 months old. That’s a long wait isn’t it? When you have a premmie for that first smile. And I, we were sitting in the car in the Sainsbury’s car park, and he just turned, I had him on my lap, and he just looked at me and he went, sort of this look of recognition came over his face and he just grinned at me, and I thought ah, ah, maybe having a baby is not that bad after all.”* (Vicky, 24:22)

> *"But as he could do more as you got responses back, like with any baby that that you get something back and you, it's a bit more giving an experience . . . Yeah, reassurance that he's okay, but also, it's not just a one-way thing of you know, feeding and changing and losing sleep. But you're also getting smiles and lifting his head and eventually you know, rolling over and all the tricks, waving and clapping. But all those milestones took a lot longer to come than with regular babies. So rather than waiting for seven weeks for a smile, I think we waited for 11 or 12. It's made a big difference."* (Angela, 3:8)

As noted above, most babies smile with conscious intention at approximately 6 weeks old. Premature babies, by contrast, will usually begin to smile only at around 3-4 months after birth. This long wait for a smile can be difficult to bear. The quotations above describe 2 mothers' experiences. For them, the smile was a sign of love and connection from the baby they had been tirelessly caring for. The first smile marked a change in their relationship with their baby; it was the start of a reciprocal relationship and a new level of bonding.

5.2.6 Mourning an intangible loss

The mothers described a tremendous sense of loss in the first year after hospital discharge and beyond. Initially they found this hard to articulate. All were grateful that there had been no tangible loss, but this made it all the more difficult to explain why they felt so bereft. This might point to the limits of IPA, whose reliance on language and verbal expression might have stood in the way of uncovering a deeper understanding, though it is hard to see what alternative there could have been that would more effectively have transferred the experience from the mind of the participant

to the mind of the researcher. However, it turned out that the opportunity for participants to grapple with the challenge of articulating and expressing their loss actually brought them to a clearer understanding of their feelings, enabling them to then express them in words. The evolution of their perspective during the interview exploration is apparent in the quotations.

With further probing, they described feelings of mourning the initial hopes and expectations of their pregnancy and a happy birth experience. As they had ultimately brought home a healthy baby, they didn't feel justified in grieving these losses; it was as if they needed permission to validate their loss and permission to grieve. They also spoke about the loss of their sense of naivety and the loss of their ability to hope for a positive outcome. These losses seemed to affect their wider perspective on life, not only their feelings as mothers:

> *"There were a couple of kids that just didn't make it and others that have serious issues, you know lifelong issues. I just think you know, the other parents need the support, not me. You know, they're the ones that deserve it. I'm just moaning that I felt a bit cheated during my pregnancy and I had a bit of a stressful few weeks to start with*." (Pam, 13:17)

> *"Because it's not something that was taken away from me, it's something that just didn't happen. So 'cheated' doesn't feel like it's the right word, but I don't know what the word is. I've missed out. But if I say 'cheated' it feels like it was taken away and it wasn't really taken away from me . . . It's hard to explain . . . It's like a loss actually. It is a loss and I guess in a way I do grieve a little for not having that full pregnancy, for not having that sort of post-birth experience, for*

not, you know, having that sort of, going into motherhood in the way that I had expected and imagined. So I suppose it is more like a loss and a grief." (Beth, 11:5)

In the quotation below Angela refers to her feelings during that first year as 'a strained happiness'. The fact that her experience could not fully meet her previous hopes and expectations meant that she could not feel complete happiness. It was a happiness with a little bit missing: a sense of loss. However, this mother was determined to enjoy her first year and to be happy. She speaks of cognitive dissonance, whereby she blanked out the sense of loss and told herself that she was happy:

"I look back and think you know, how did I cope? And um, yeah, like I had thought that I was on cloud nine, but actually I think it was a bit of a strained happiness. . . . I think it was, the fertility thing played a lot into it. I was determined to be happy and we wanted this baby for so long that I was determined to be happy. . . . but yeah looking back it was it was a strained happiness." (Angela, 3:18)

5.2.6.1 Permission to grieve

Despite having emerged from a significant trauma, the positive outcome and taking home a healthy baby made it difficult for these mothers to justify their sense of loss. Having faced the potential of losing their baby, pain about the loss of a full-term pregnancy and a happy birth began to feel trivial and shallow:

"*Yeah, and that is all ridiculous really sort of when I'm verbalizing it now, I'm thinking how ridiculous does all of this sound? But it's kind of how I felt. So I'm sorry. It probably sounds really shallow that I'm worried about the fact that I didn't have this big bump, and my baby's alive. So I should really just be . . . don't know, yeah, makes it hard to feel deserving of help."* (Pam, 7:16)

"Well I suppose part half of me feels that I didn't get to experience pregnancy to full term. So that last third trimester, I don't know what that's like and I didn't get to hold my baby until she was, well, for a day, so she was 24 hours old. Then holding a baby that had lots of wires attached and, and then when I did want to hold my baby I had to ask to hold her, and could only look at her through a plastic box. So I feel like it's . . . The only word I can think of is cheated, but I don't, it's not the word I feel is right. But you know I missed out on that . . . those experiences that you expect when you're pregnant and you're anticipating becoming a mum." (Beth, 7:24)

Grappling with her sense of loss, Beth tries to reconcile feeling cheated with her acceptance of an experience she recognises was beyond her control.

"Because it wasn't taken away from me, I don't feel it's something that happened to me. Nobody took it away . . . I don't know um, an expectation I guess, but hard to kind of contemplate loss of something that was never to be. Yeah, I suppose but the expectation and the hope of what it was to be. Yeah, didn't happen. Yeah, because it was sudden, you know, there was no warning. It happened." (Beth, 11:19)

Their comparisons had shifted from comparing their experiences to the best-case scenario to comparing them to the worst-case scenario. They describe feeling pressure to be grateful for their baby and that nothing worse had happened. Many of them had watched other babies die on the NICU or witnessed the reality of other babies enduring complications and side effects that would render them disabled for life. When Nicole reached out for help, she felt completely dismissed and felt accused of being selfish and ungrateful.

> *"There was no support mentally for me coming out and I sort of had this impression; I can't really talk about my experience because they say 'oh, well, it's normal to feel like that because you've had a tough time, but just concentrate on your baby's getting better.' Or 'Well, not everyone gets to bring a baby home' or 'not everyone's as lucky as you, sort of'. If I try to say anything, it's just well, you're being selfish. 'How dare you think about yourself and your well-being because at least you get to bring your baby home' I mean when we were bringing him home, there was a baby living next to us and the parents were saying goodbye . . . I didn't feel like you can say by the way, I'm not okay either, when somebody's just lost their child next door."* (Nicole, 12:15)

These experiences appeared to leave little or no room for grieving over the very real losses these mothers had experienced. This was compounded by the feeling that those around them who had not had the same or similar experiences could not possibly understand what they had been through. It seems they experienced others as relating to them only in the present moment, with a tiny but healthy live baby in front of them. They apparently felt that others could not relate to or understand the trauma

that had preceded homecoming and therefore perhaps found it difficult to empathise with them.

The mothers spoke as if they needed permission to grieve. They needed acknowledgment that although the object of their loss was not physical or quantifiable, their feeling of loss was real and they were entitled to mourn the loss of the expectations, hopes and dreams they had had for their pregnancy and birthing experience. Another element of this that seems important is the space to do this grieving and to talk about their experience and feelings of loss without being judged by others.

> *"It's nice to have someone that you can just talk. . . just get something off your chest too and they don't judge you or go. Well, you know, sometimes you don't just want to hear someone saying don't worry about it. You just want them to listen to you. Nod their head, and kind of that's that. You know."* (Pam, 8:14)

5.2.6.2 Loss of trust in the body

Angela shared how after being unable to conceive for some time and suffering a miscarriage, she had lost all faith in her body. Knowing that her body had been so unpredictable left her with little trust in it, but also with little trust in her son's physical ability to survive. This left her with a feeling of uncontained fear and desperation for her son's survival:

> *"I didn't trust myself being pregnant after the fertility stuff. I trust myself holding a baby and caring for a baby, but I didn't trust my body with that whole fertility*

experience, and I had no trust of my body whatsoever. So, yeah, I was quite pleased he came early but it sounds strange." (Angela, 12:29)

This mother's reflective realisation shines a light on a difficulty that all 8 mothers may be enduring. Being let down by the body in the seemingly automatic, basic process of childbirth can either consciously or unconsciously introduce a realisation of the body's fragility and limitations. Furthermore, when participants did not trust their body to function as it should, they became acutely aware that they were unable to do anything to actively control its functioning. So perhaps while this idea is focused on the baby during this premature birth experience, there may also be another layer of anxiety at work that focuses on a personal fear of inhabiting a body that can be unpredictable and beyond our control.

This was highlighted when Nicole shared very strong feelings about her birth experience and how she felt that she had had no control over her own body:

*"So I kind of felt like I'd been stuck, I wasn't strapped down, but I wasn't allowed to move. I'd had no control over my own body." (*Nicole, 11:22)

Nicole implies not only a loss of control over her body, but more broadly, over the situation she had been thrown into, together with loss of control over the baby, as explored below.

6.2.6.3 Loss of control over the baby

When a premature baby is born, care is transferred to the hospital staff and the mother has little say or control. This is medically the safest route to the baby's survival, but it can be difficult for mothers to experience. Many mothers referred to this loss of control during the NICU stay. The following excerpts relate to different stages in Nicole's first year of mothering, showing how her lack of control over her baby's treatment had a long-term effect on her, lasting for months:

> *"Then my child was taken away from me. And then after a week he was moved to another NICU and then after that he was moved to another NICU."* (Nicole, 11:23)

> *"I have this feeling of like taking my baby away from me and even when he came home, and everything was okay, it was still in the back of my mind. I didn't have any control over my medical situation or what happened to him, uh because they weren't like are you okay if we move him, it was just like you'd get a phone call like oh, he's in an ambulance on his way to somewhere else"* (Nicole, 11:31)

> *"But I was by that point. I was, I was really ill. I was convinced that people, kind of people were following me; even if there was just traffic I'd think they were following me because they wanted to try and kidnap him and they want to hurt him or to take him away from me . . . and then to be told well, we can't do anything. It was a really awful experience."* (Nicole, 13:2)

5.2.7 Mothering in the wake of trauma

These reflections clearly show that the initial trauma of premature birth influenced the participants' mothering journeys throughout the first year. All describe how the trauma only hit them many months later and it was only at that point that they began to process what they had been through. They describe realising how their experience had changed their perspective on life in general and that this made it difficult to connect with their day to day lives, friends and family as they used to. This was the time they felt most alone. They all felt that emotional support was necessary and important during this time, and those who had accessed therapy had found it helpful. These ideas are explored further below.

5.2.7.1 Rooted within the context of the NICU

It is noticeable in every interview that all 8 mothers automatically reflect on the NICU experience to answer many of the questions about their experiences in the first year after discharge. Eleanor noticed this pattern in her own answers and at one point commented that her answer could only be fully understood if she first gave the context, beginning with an experience during the NICU stay:

> *"You're talking about after the hospital I thought you were talking about now. Okay. So but just as a pre-, just as a foundation for that, we were in the hospital . . . ."* (Eleanor, 4:14)

> *"I feel like you keep asking about after the hospital which is fine because that's what you're . . . but for some reason I keep on going back in the hospital, but*

that will lead to answering your question about when he's out the hospital." (Eleanor, 8:3)

This offers valuable insight into how the first year of mothering can only be understood in the context of the original trauma. They were unable to articulate their experiences without placing them in the context of the trauma of the birth and the NICU.

5.2.7.2 Delayed processing of the trauma

All 8 mothers described how they later realised that they did not fully acknowledge the seriousness of what they had been through until weeks or months after the birth and after their hospital discharge. When reflecting on the NICU experience they remembered a constant, continuous servitude to the baby and its needs. Caring for the baby and nursing it to independence and health was evidently the sole focus of their existence at that time. As discussed above, they described a sense of shock, fear and numbness at the time, and the autopilot system that took over their behaviour. Only on looking back were they able to consciously comprehend the extent of the danger and loss they had faced during those weeks.

The mothers explain that it was during the months following discharge, when the intensity of the danger and the fear reduced somewhat, that the severity of their experience began to set in. Heather explained that as the worry began to subside it made space in her mind to process what she had been through:

"It was just me just sitting there, just . . . just me and my thoughts and I think that combined with going back to the office and seeing all the people . . . that

was the start of actually feeling quite bad about what happened um, and um, yeah, I had a couple of months of sort of you know, finding myself getting more and more tearful about it all . . . um, just to myself and then I thought you know, it can't go on like this really and I made contact with a psychologist." (Heather, 6:18)

Angela and Pam recall very similar experiences:

"Yeah. It was after that first year when you know sleep was pretty settled and he was just an easier happier, baby. I think we looked back at it and were like, 'it was really quite tough. How did we get through that?'" (Angela, 10:14)

"It was only as I said probably around the six months stage, that it sort of hit me and well hit me is a bit . . . it kind of just crept up on me really and it was in that stage. I guess it maybe it would have helped if somebody, if the health visitor had said, you know, are you still alright, and how are YOU? But they don't really ask how YOU are. It's more about, you know, how's the baby and is he still feeding okay? Or are there any issues? It's all about physical things really." (Pam, 9:10)

This space and processing introduced thoughts about personal responsibility for the early birth and feelings of guilt and shame. It was during these months of reintegrating into society that the mothers began to realise the losses they had endured, such as a positive birth experience and a rightful place in an NCT social circle or similar setting. It was also during this phase of social reintegration that the disparity between their

experiences and those of others became more obvious. These elements might have contributed to the feelings of isolation and loneliness discussed in other themes.

Taking all these elements into account, it is possible to begin to comprehend the massive task these mothers faced in this first year, processing the trauma they had endured, adjusting to their new role of mothering their premature baby, and trying to build a new way of relating to their baby and the world around them in the wake of their experiences and their new existential understanding. This is an overwhelming responsibility and must take place in tandem with ongoing worries about their baby's health and development.

5.2.7.3 A permanently changed worldview

All the mothers reflected on how their experience of the trauma had changed their perspectives on life. Having faced their own mortality and grappled with the reality of the unpredictability of life, their approach to life had changed forever. Each mother described this in a different way according to their own subjective experience, but it was clear that for all the mothers their new existential awareness demanded a more existentially authentic approach to life. They also noticed that this separated them from friends and family, whom they perceived as remaining in a more naïve state of existence. Heather's reflections on her broadened worldview below is an accurate representation on the altered existential awareness shared by all the participants.

> *"I think in some ways my perspective on life is really altered and I just, it was weird because like on some levels I think I became serious about everything because you know being like this crazy life-changing experience. Then on other*

levels, I quite I was just like yeah, let's just enjoy life. Let's relax. This is brilliant. Don't sweat the small stuff. Yeah. So I dunno, I do feel a bit, feel bit different too. I feel like, I do feel that I still feel a bit different to other mums my age . . . and I still even like five years down the line, I still feel like that pang of 'oh, you know, there's' I feel like they have a sort of innocence, but I just got totally taken away from me . . . But then in other ways, I'm just so like massively aware of you know, that they almost weren't here especially my daughter. I don't know. I just think I'm just a bit of a . . . I think it has altered my perspective on things and the way I am as a mother. I'm just I don't have that kind of . . . I don't know. I'm not really sure how to describe it." (Heather, 13:4)

After a traumatic experience, a period of adjustment is needed to develop a new way of interacting with the world. The first year of mothering a new baby is an adjustment in its own right and managing these two adjustments seems to have been a heavy challenge for these mothers. The mothering relationship requires bonding and emotional investment which, as we have seen in previous quotations, may not be an instinctive response when one is faced with the realities of death and loss.

5.2.7.4 The need for emotional support

All 8 mothers opined that therapy would have been helpful in the first year after hospital discharge. The themes and perspectives collated above indicate a need for emotional support from various angles. However, perhaps most important in this research is the directly expressed need for emotional support from the mothers themselves:

"Yeah. I mean they offered, they offered counselling, in the hosp - sort of vaguely offered counselling in the hospital. But um, I think it was very clear actually post birth, that I did need something um, but um, they were a bit . . . yes, I certainly think um, that maybe they should be a little bit more proactive." (Vicky, 30:19)

"So, it took me a while, but I ended up . . . that's when I went to the GP and she said like I can't help you . . . It was a really awful experience" (Nicole, 13:1)

For Pam, the realization that support was needed emerged only much later:

"I probably didn't even realise that I needed help or to talk through it with somebody if you know what I mean . . . I think it's different if . . . if someone had said to me at that stage, you know, some mums feel like this, you know, are you having any of these thoughts or feelings? I would have probably spoken about it then." (Pam, 12:15)

The importance and value of specialised support was also emphasised as can be understood from Heather's quotation below.

"Someone with sort of specialist experience of that environment because I felt like the way I felt was definitely related to what happened there and uh, you know, and after you know, it's yeah, it's a journey. There's, there's always things that that come along related to prematurity all through your child's life." (Heather, 7:27)

Further evidence of this need is that four mothers actively pursued therapy from their NHS provider. Their accounts suggest that the professionals they approached failed to make any provision for support. In fact, in two cases they actively dissuaded the participants from pursuing therapy or explained that no support services were available to them. This led to the mothers feeling that the severity of their experience had not been acknowledged. Vicky recalls being told that she was coping and that everything was fine despite what she may have thought.

> *"And if you say actually no I'm not coping, they look at you and go, 'no but you just strung a sentence together, you're fine, you're not crying on me. Women cry when they're not coping so, go away, you're alright."* (Vicky, 10:33)

Sadly, Nicole was met with a similar response when in fact she was desperate for help:

> *"I went to um, my GP and said look, I'm not feeling right and she just sort of said well, it's too late to do anything now . . . um . . . because for perinatal support the NHS only provide up until your child's first birthday . . . So I was just kind of left, you know with nothing . . . I was just sort of left floundering."* (Nicole, 10:23)

These type of responses left the mothers feeling a lack of validation and led them to question whether their emotional response was disproportionate to the circumstances.

"So I felt very well supported when she was in hospital and I utilized that support a lot and then when we were discharged there was no pointers towards any . . . like no one said, oh if you feel bad get in contact or I suppose the system is, you know, if you feel bad you should contact your GP?" (Heather, 7:17)

There was evidently a common judgement that their experiences were 'not bad enough' to warrant an emotional response or to be deserving of help. This echoes the earlier theme of falling through the cracks, when participants' difficulties were not considered severe enough to receive high-level support, although they were also patently not well enough to continue with mainstream provision and expectations.

"You probably need a lot more support because you need someone to say it's fine, what you feel is normal that if you're worried about bonding that's normal. It will come to you in time . . . It's little things that like that make a difference and it makes you feel less of a bad mom." (Anita, 20:11)

Anita's words sum up the overwhelming view that support was necessary and could have made a significant difference.

5.3 Summary

The findings presented in this chapter present a moving account of participants' traumatic and terrifying experience of mothering their very premature baby in the first year after hospital discharge. 7 superordinate themes emerged: 'The second set of horror'; 'The isolation of limbo'; 'Attachment to the NICU'; 'Feeling like a mother came

later'; 'Bonding in the shadow of the threat of loss'; 'Mourning an intangible loss;' and 'Mothering in the wake of trauma'. These themes highlight how the mothers' fears of their baby dying became overwhelming, overshadowing any enjoyment of their baby or of becoming a new mother. All felt a tremendous sense of responsibility to keep their baby alive and the fear of loss affected the way they were able to bond and relate to their baby. The inevitably protracted nature of the baby's development meant that there was a long, anxious wait before their fears could be resolved. Their heightened awareness of life's fragility resulted in feelings of generalised anxiety and fear of illness and harm.

The unusual circumstances of the birth and the NICU experience made it difficult for the mothers to relate to others who could not fully understand what they had been through, never having undergone this experience themselves. This left them feeling isolated and alone. Access to medical information and support was limited, leading to feelings of desperation and despair. They felt a pang of longing to belong and were drawn back to the NICU, where they knew they could access much-needed practical support, and where they felt acknowledged and understood.

All the mothers felt a deep sense of loss, though they found it hard to reconcile this with gratitude at having brought home a healthy baby. Nonetheless, they found themselves grieving over the loss of a full-term pregnancy and of the joy of a normal healthy birth. It was only months into the first year, when the immediate danger had subsided, that they began to contemplate the enormity of the trauma they had experienced.

As the rich quotations suggest, the mothers yearned for acknowledgement of the trauma they had undergone; they also needed to be listened to without judgement. They wanted their confused emotional state and need to readjust their perception of life to be validated. Much of this need was addressed by the peer support they all sought and gave to others. However, they also expressed a need to be supported by a professional with knowledge and understanding of their needs. Perhaps, given the anxiety and unpredictability that had marked their journey, being held by a knowledgeable professional with therapeutic boundaries becomes all the more important.

The themes that emerged from the data are inherently existential and the participants' experiences resonate with several concepts in existential philosophy and psychotherapy. With its focus on the existential limitations of existence; man's inherent fear of death; the pain of loss; choice and responsibility, and man's ultimate aloneness and desperation to belong, existential psychotherapy is extremely relevant to the exploration and understanding of the emergent themes in this study.

Existential therapy delivered by a qualified professional can draw on existential philosophical and psychotherapy concepts to support mothers of premature babies in making sense of their experiences and emotional response. A trained therapist could support them in processing the trauma they have experienced and help them navigate a new path that is more congruent with their new existentially authentic outlook. The therapeutic space could provide a place for such mothers to consider complex feelings around bonding and mothering and to normalise individual feelings and experiences.

As evidenced throughout this analysis, this could satisfy many of the needs identified by these participants.

6. Discussion

This study has investigated how 8 women experienced mothering their very premature baby in the first year after hospital discharge. The aim of the study was to gain insight into each mother's personal and individual experience of this journey and what this experience means for them (Willig, 2008) and in so doing, identify areas where help and support can be provided to other mothers of very premature babies. Interpretative Phenomenological Analysis was used and 7 superordinate themes were identified. As an existential psychotherapist I carried out my phenomenological exploration through an existential lens and I identified strong existential themes within these findings.

My study found that the experience of a very premature birth and subsequent NICU hospitalisation does affect the experience of mothering these infants in the first year after hospital discharge. The 7 superordinate themes that emerged from the data reflect how the emotional repercussions of a very premature birth introduced an existential crisis for my participants that influenced the way their mothering relationship and the mothering identity evolved slowly and tentatively over the ensuing months. The following discussion presents an existential exploration of my findings in the context of the literature.

6.1 The aftermath of existential shattering

6.1.1 Mothering after the trauma of very premature birth

'Existential shattering' is a concept introduced by Tom Greening to describe the emotional consequences that follow existential trauma (Hoffman & Vallejos, 2019). Hoffman and Vallejos explain that "Existential shattering is the sudden and

unexpected dismantling, or shattering, of one's self-conception and worldview as a consequence of an event or process that the individual has experienced." (Hoffman & Vallejos, 2019. P1). My experience of being with my participants and hearing their stories convinces me that they experienced their premature birth as an existential trauma that shattered their perception of birth, motherhood and existential security. The trauma of premature birth and the NICU experience exposed them to total existential vulnerability and their sense of safety in the world was ripped from underneath their feet.

Of course the reality of our existential vulnerability remains constant at all times, but although death is possible for all of us at any time, it's difficult to engage meaningfully with life if we are focused on our looming mortality all the time. As Jaspers explains when he talks about our denial of existential limitations 'In our day-to-day lives we often evade them, by closing our eyes and living as if they did not exist. We forget that we must die, forget our guilt and forget that we are at the mercy of chance.' (Jaspers, 1951, p.20). Most people live in this state of existential denial because acknowledging the fragility and volatility of existence can be so terrifying. The mothers in my study found that their trauma was a stark reminder of the reality of mortality that became impossible to deny and they became preoccupied with lurking possibility of death and tragedy. This emerged several times in the interviews with all the mothers. Nicole exemplifies this transition into a new and frightening mind-set: "Of course, babies will walk and talk. You never think that your child won't be able to do all these things . . . It's not something that you really think you could end up being in . . . that kind of world, and it's just it's a terrifying thing . . . You don't know if they're going to be okay." (Nicole, 19:6)

6.1.2 Using Trauma as a lens

As this research is an exploratory phenomenological study, I had initially proposed an open title that simply included ‘The experience of mothering a very premature baby in the first year after hospital.’ However, during the initial stages of planning my proposal I was strongly advised by the Programme Approval Panel to reframe my study as exploring this experience through the lens of trauma. At first, I was concerned that my phenomenological study would be affected by approaching the research from a preconceived framework. After careful consideration I was satisfied that this approach was actually strongly supported by the literature, which unanimously identifies the experience of very premature birth as a trauma. Using trauma as a lens served to frame the initial experience within these parameters but my exploration of the months following remained opened and phenomenological. On reflection, having completed the study, the trauma element emerged so strongly from the data that whether or not I had referred to the ‘trauma lens’ in the title became irrelevant, as the outcome of the study would have been exactly the same.

Becoming a mother is always considered a major life stressor, both physically and psychologically (Miller and Sollie, 1980; Kristeva, 1986a; Beauvoir, 1997; Butterfield, 2010; Arnold-Baker, 2015). My participants described their experience of very premature birth as sudden and traumatic. Heidegger (1996) introduces the concept of thrownness, noting that it is inevitable that in life we will find ourselves thrown into situations we will be unable to change or affect, starting from our very birth. My participants’ experience of sudden and unexpected very premature childbirth is a prime example of being thrown into motherhood. It could be neither planned nor

changed and this journey introduced thrownness on many dimensions. Not only did they have to contend with the usual complex transition to motherhood, but they were also thrown into a confrontation with core existential phenomena such as birth, death, suffering and responsibility, and they found themselves in a state of confusion and numbness. They had been thrown into their long-awaited experience of the miracle of birth but it was immediately swept into insignificance as they suddenly faced the potential of their baby's death, which completely consumed their emotions.

The mothers describe the pain and guilt of being helpless to protect their baby or even comfort it and I could sense their slow, shocking internalisation of the terrifying reality that all these elements were beyond their control. It is not surprising that all the mothers described feeling intense fear and anxiety and that some felt responsible for causing the baby's early arrival and putting it in danger. They were in a head-on collision with what Yalom (1981) would term the 'inevitable limit situations' of life and their fear and anxiety can be attributed to their sudden realisation that man is subordinate to these limitations; we do not possess the control we fantasise about having.

After coming face-to-face with this reality, all the mothers found it very difficult to suddenly forget about their baby's mortality; instead, they were overwhelmed by a sense of impending death, bringing constant fear and anxiety. Facing this limitation also reminded them of their own mortality, which introduces another layer of fear and anxiety. Pam's description of her anxieties as her baby slept at night gives a rich understanding of how awareness of the possibility of imminent and unexpected death lingered throughout the first year:

> *"I used to go and check on him before I went to bed to feel him, make sure he was still breathing. If he'd slept through the night. I'd panic, you know, has something happened to him and I would want to go in there and check on him, but not wanna go in case, you know, something happened during the night."* (Pam, 3:7)

This typifies the experience of all the mothers, who shared very similar memories of their fears during the first year. I noticed in the interviews that all the mothers automatically reflected on the NICU experience to answer many questions related to their experiences in the first year after discharge. This confirms how the initial trauma influenced their experiences going forward. I got a strong sense from all the mothers that they felt that their experience can be fully understood only by someone who has been through it themselves or has been involved with the experience first-hand in a medical capacity. This suggests that their first year of mothering can only be understood in the context of their original trauma.

All the mothers described how they later realised that they did not fully acknowledge the seriousness of their ordeal until weeks or months after the birth and after hospital discharge. It took time for them to process the magnitude of the trauma and it was during those months following discharge, when the intensity of the danger and the fear reduced somewhat, that the impact of their experience began to set in. Heather explained that as the worry began to subside it made space in her mind to process what she had been through: *"It was just me just sitting there, just . . . just me and my thoughts and I think that combined with going back to the office and seeing all the people . . . that was the start of actually feeling quite bad about what happened."* (Heather, 6:18). This was also true of Angela and Pam: *"It was after that first year*

when you know sleep was pretty settled and he was just an easier happier, baby. I think we looked back at it and were like, 'It was really quite tough. How did we get through that?" (Angela 10:14)

One way of understanding my participants' emotional response could be through the medical diagnosis of PTSD. Some of their accounts do meet the criteria listed in the DSM-5. However, diagnostic criteria are not relevant to this research as the aim here is to gain insight into the individual, and a nuanced experience of this phenomenon, rather than to categorise or create meaning through a preconceived framework. Statistics show that only 16% of mothers of premature babies are diagnosed with PTSD, while 80% report that their mental health suffered significantly after the premature birth (Bliss, 2020). This indicates that the diagnostic criteria for PSTD may not be sufficient for identifying the emotional struggles encountered in the first year after a premature birth.

My participants' raw descriptions of their feelings of fear and isolation following discharge suggest that the intense emotional experience does not end with NICU discharge, but that the initial trauma of the early birth experience and hospitalisation influences the way these women relate to being a mother and mothering their baby throughout the first year.

6.2 What does it mean to be a mother?

The transition to motherhood through the birthing process is a bridge between being in the world and being in relation to another. Giving birth is the closest one can get to being both self and other. Each mother in my study had carried her baby as part of

herself and was then suddenly thrust into an intense interpersonal relationship with this baby, who came from her, but was also in many ways a stranger whom she had to get to know. Beth captures the complexity of this transition. Listening to her discuss her early memories of meeting her daughter, I got a strong sense of warmth and closeness, but also bewilderment and distance: "*And I think it I just felt it was like looking at a stranger but a stranger that was very much a part of me, that had come from me. So it's quite an unusual feeling and experience"* (Beth, 10:21). Existential literature on transition to motherhood explores the importance of the third trimester of pregnancy as a time for the mother to adjust to the idea of the end of the pregnancy, the physical separation from her baby and the start of motherhood and caring for her dependant baby. These adjustments are considered important for the development of an identity as a mother (de Beauvoir, 1997; Kristeva, 1986a).

For my participants labour happened suddenly and unexpectedly. They had not mentally prepared themselves to give birth or to meet their baby. The third trimester and the important opportunity for adjustment was suddenly stolen from them and could not be replaced. The mothers describe the shock and disbelief they felt when they saw their baby for the first time and how they could not comprehend that they were the mother of the baby they were looking at. As Angela so vividly describes: "*Like my first reaction was wow, he's amazing. He's so gorgeous. Where's his mum and dad? Uh, is that me?*" (Angela, 4:28). This was far from the euphoric highpoint they had been imagining and expecting and the void of emotion was experienced as traumatic and surreal. Amid the trauma the mothers could not understand their lack of emotion; this caused them to feel guilty, inadequate and confused. They were left questioning what it was supposed to feel like to be a mother. Vicky still finds herself asking that question

today: *"Oh, I still don't think I'm one! I still, still look at him and think 'I'm your mother? Really'?*" (Vicky, 12:1)

Sartre (2003) proposed that existence precedes essence, suggesting that in the first instance we simply exist, thrown into the world at birth with no particular purpose. He argued that we continue to be physically present, whether or not any purpose, meaning, or direction in our existence precedes our essence. I reflected on the thought that simply through the physical process of giving birth, my participants had suddenly and unexpectedly become mothers. The intellectual concept of becoming a mother implies a transformation of self and the formation of a new identity. However, in the early days after birth, my participants recall no emotional transformation and they were shocked that they had felt nothing at all. Beth's recollections gives a vivid picture of the common experience following the birth: " *I think it took a while for me to sort of, sort of develop those feelings and emotions, like not emotions . . . maybe there are some emotions, because when I first met her I felt nothing and it was quite strange* (Beth, 8:4). All my participants shared this experience of numbness and lack of emotion about being a mother to their new baby. All described their early mothering experience as 'going through the motions (Nicole, 20:21), or 'being on automatic pilot' (1:25). According to Sartre, one's engagement with their surroundings, their response and reaction to the world around them creates purpose and meaning and becomes their essence.

Through giving birth prematurely my participants were thrust into mothering a very premature baby without any choice or warning. These reflections reminded me of Sartre's theory because it is as if following the birth their status as mothers was a physical state for which they had not yet had a chance to create a sense of meaning

or purpose. The mothers describe how their emotional connection then developed slowly over time through their relationship with the baby and their response to their situation and environment. Through their interaction with the baby a meaningful and purposeful relationship began to develop, giving essence to their status and experience as a mother. This is also supported by Merleau-Ponty's (2012) theory that physical engagement is the foundation of experience, with thought following on from this to make sense of what we have encountered.

Research reports similar emotional responses in other preterm mothers when seeing their baby for the first time. Mothers wanted to connect with their babies and found themselves trying hard but failing to do so. Some attributed this separation to the literal separation of the plastic box that separated them from their baby, while others describe an emotional separation (Golish and Powell, 2003; Gunter, 2010; Hall et al, 2013). Golish and Powell (2003) describe mothers as being in denial that the baby was theirs. This sense of denial of being the baby's mother did not emerge from my research; rather, events happened so quickly that it took time for the mothers to process and assimilate what had happened to them, causing a delay in the development of their emotional response.

Mothering on autopilot is a new theme that has not been highlighted in previous research. While the research speaks of the overall lack of connection between mother and baby, my participants found that practical care came easily and automatically. In the early weeks at home participants recall caring for their baby as following a care regime by rote rather than a spontaneous expression of love and care. It is this element that sets my findings apart from those of previous research. The need to engage practically with the baby was immediate and held serious consequences. This may

explain why the mothers engaged with this care whether they felt ready to or not. However, engaging with the baby emotionally was perceived as having less immediate consequences and could therefore take the necessary time to develop. Over and above this, an emotional connection would not be possible to engage by rote as by its nature this can only develop at its own pace. This is evident in previous research, in which mothers describe trying hard to connect with their baby but being unable to do so (Golish and Powell, 2003; Hall et al; 2015; Spinelli et al., 2015).

In my research some mothers attribute their initial response to the early birth and the loss of the experience of skin-to-skin contact directly after birth. They also described their babies being '*whisked away'* (Angela, 4:25) for urgent medical attention before they could see or connect with them in any way. The mothers were also clearly in a state of shock, which perhaps added to their inability to feel for their babies. These perspectives echo those found in previous research (Golish and Powell, 2003; Beck 2004; Gunter, 2010; Hall et al., 2013), where mothers are described as feeling shocked and overwhelmed, and unable to link their emotional response with the situation they faced. Some considered whether the hospital environment had perhaps made the care seem more medicalised and structured, and whether feeling assessed by hospital staff perhaps disturbed the natural evolution of the care-giving. This point is also explored by Spinelli et al. (2015). Others in my study thought that perhaps the fear of the babies' fragility and the lingering fear of loss made it difficult for them to allow themselves to connect emotionally to their babies, for fear that they might still lose them. This supports earlier findings that the fear of losing the baby affected the ability of parents to connect with their baby (Golish and Powell, 2003; Gunter, 2010; Hall et al., 2013).

6.2.1 A natural connection

While previous research focuses more on mothers' disconnection and inability to bond or feel anything for their baby, my research suggests that mothers did feel a connection with their babies, though it was different from what they had expected to feel. They seemed to adapt to the unexpected mothering task and bonded in the way that came naturally to them at the time. The expression *'tiger mother'* used by Angela (Angela, 6:1) seems an accurate description of the primal, instinctive bond the mothers described feeling for their babies. Although it was not as gentle or tender as they had expected, they could recognise an undeniably intense bond with their baby and a fierce sense of protection and desperation to help it survive. Although the term 'tiger mother' is also used colloquially to refer to a strict, relentless style of mothering in Chinese culture, after careful consideration I decided that in the context of Angela's interview, she was referring to a sense of fierce protection and visceral determination to ensure her baby's survival. Although this was not what Angela had expected to feel, her account shows that she does recognise her relational response as 'being a mother' even though at the time she was not yet able to conceptualise and accept this broader definition of what it might be like to be a mother.

7.2.3 The importance of reciprocity

Reciprocity was an important factor in the development of a more familiar emotional bond. The mothers recall how the baby's long-awaited smile and social interaction marked a change in their feelings towards their baby and their emerging feelings of being a mother. When the baby began to respond it was like a reward for the mothers' hard work and validation that their efforts had meaning and purpose. Previous

research also refers to the baby's first interactions as significant in the developing identity of the mother; Gonzales and Espitia (2014) report that social and motor developments including smiles and giggles were described by mothers as the happiest moments since the baby's birth.

Reciprocity has not previously been highlighted in research into premature parenting as a significant point in the development of bonding or the formation of the mothering identity. This new finding therefore sheds light on existing research. My findings are similar to those of Arnold-Baker (2015), who researched the transition to motherhood for full-term mothers. Arnold-Baker (2015) found that full-term mothers also valued the start of social interaction with their babies and that this reciprocity was a significant point in their developing identity as a mother.

The bonding process of the mothers in the current study can be interpreted through the lens of Martin Buber's theory of the 'I-Thou' versus the I-it' relationship (Buber, 2000). Buber proposes that the 'I-Thou' relationship is a wholly reciprocal relationship in which both sides fully experience the other. In contrast, the 'I-It' relationship refers to a simply functional relationship between a subject and object. In the 'I-Thou' relationship the 'I' captures the essence of the interaction and shapes the context of the relationship. Conversely, Buber suggests that when relating in an I-it relationship one holds back something from oneself (Buber, 2000).

The mothers in my study describe the first few months as a one-sided, largely functional relationship lacking in mutuality and enjoyment. During these stages they found it difficult to feel a bond or connection to their baby. However, when the baby

began to respond, and the relationship became reciprocal they were able to relate to the baby as another person and began to feel a more familiar kind of emotional bond developing.

When I asked Vicky about her experience of bonding with her baby, her response was *"I don't know, what's the definition [of bonding] anyway?"* (Vicky, 25:1). This question represents the feelings of many of the mothers in my study, all of whom have been exposed to the fact that forming a relationship with their baby is in reality a lot broader and more subjective than a new mother might be led to expect. This is also likely to be true of all mothers, regardless of their varied birthing and early mothering experiences, particularly those who have given birth in traumatic or difficult circumstances. As existential philosophy suggest, it is the way a mother relates to her baby and the meaning she ascribe to her relationship with her baby that creates her essence as a mother (Heidegger, 1996; Sartre, 2003; Merleau-Ponty; 2012; Van Deurzen, 2002). As Heather expresses so powerfully, *"I feel like physical separation was sort of compensated for by just pure, you know desperation and love towards her and it all worked out all right in the end"* (Heather, 16:1).

6.3 Guilt responsibility and the illusion of control

6.3.1 Guilt and responsibility

Seven of my participants spoke about feelings of guilt and failure about the birth. They felt guilt at not having been able to carry their baby to term and felt that it was their fault the baby had had to endure all this pain and hardship. They felt they had failed in the mothering role. There seemed to be a cycle of struggle between knowing that it

wasn't really their fault and strong feelings of guilt. As Anita remarks, *"And then you just feel guilty. It's my fault she came early. You know, what if she hadn't come early? She would be fine. You go through those transitions when you know, it's not your fault* (Anita, 10:22). These findings complement previous research showing that after a very premature birth mothers experience feelings of guilt and failure (Golish and Powell, 2003; Gunter, 2010; Hall, 2015; Raines, 2015; Spinelli et al., 2015).

The mothers felt that their failure in their duty to carry their baby for the full 9 months of pregnancy had caused their baby's suffering and risk of death. Post-birth is such an important time for developing an identity as a mother, and they entered this transition having already failed at the task (Kristeva, 1986a; de Beauvoir, 1997; Butterfield, 2010; Arnold-Baker, 2015; Spinelli et al., 2015). The idea of motherhood is filled with preconceived expectations and generalisations from some common experiences of pregnancy and birth. These ideas conjure a meaning of what being a mother is like and what it entails. Mothers of very premature babies do not experience pregnancy and birth in these expected ways, and this seems to make it difficult for them to feel like or recognise themselves as mothers. Nicole's feelings of failure and guilt were so extreme that she questioned whether she even deserved to be a mother. This raises the question of what 'being a mother' means. Nicole had given birth to her son and was physically unquestionably his mother; however, in Nicole's mind a mother was someone who carried their baby to term and protected it from harm, and as she had not fulfil these requirements she felt she could not be a mother:

> *" . . . a sense of feeling like I didn't deserve to be his mum, because I felt like I was the one who put him in that position so there was this overwhelming*

sense of guilt for me as well, um, you know like I failed him, my body failed him" (Nicole, 16:16)

These women were of course mothers but had experienced a completely different birth and mothering experience than they had expected. They had no mothering schema to relate to that included their type of experience. Feminist existential philosophers have explored the notion of the socially constructed idea of what it means to be a mother and suggested that rather than being a socially prescribed state of being and action, motherhood is really a more fluid and subjective experience (Kristeva, 1987; de Beauvoir; 1997; Butterfield, 2010). These philosophers are referring to motherhood after a full-term birth and a mother's expected role, relationship with her baby and changed role in society. However, I feel that the premise of these ideas is also relevant here, where we are considering a different kind of mothering experience that deviates from the expected path. The concept of a fluid and subjective sense motherhood provides a more open and inclusive idea of what it means to be a mother and the range of physical and emotional experiences that a new mother might encounter. This could offer a comforting and supportive frame of reference for new mothers of very premature babies.

Previous research also speaks about mothers feeling guilty about things they might have done that could have caused the early birth, thereby making them responsible for their baby's suffering (Golish and Powell, 2003; Gunter, 2010; Hall, 2015; Raines, 2015; Spinelli et al., 2015). My participants do mention having had thoughts about whether they could have done anything differently, but it seems they had been able to resolve those questions early on.

6.3.2 The illusion of control

The feelings of guilt and responsibility are so intense, yet the truth is that the phenomenon of very premature birth is beyond human control. Yet although accepting responsibility for the birth is so painful and traumatic, mothers seem to prefer this acknowledgement of guilt to the more terrifying prospect that we are subject to random chance, suffering and tragedy which render our attempts to control our lives futile. Although it is in reality unreasonable to accept responsibility for something beyond our control, accepting this responsibility therefore also gives them a sense of control over a world that suddenly seems dangerous and unpredictable. My participants describe how the first year at home was dominated by monitoring and vigilance to keep the baby alive and safe. While this is certainly related to the reality of the baby's fragility, there also seems to be a sense that if they are extra careful and extra vigilant, they can gain control over illness, death and loss. Research has identified similar findings, with mothers describing an intense focus on saving the baby from dying (Golish and Powell 2003; Gunter, 2010; Gonzales and Espitia 2014; Spinelli et al., 2015).

The weight of this responsibility is massive for the mothers and this, coupled with their new existential understanding of how unpredictable and dangerous life can be, leaves them in a state of intense fear. This fear affects their confidence in all areas of mothering and they continuously question whether what they are doing is correct or good enough. It seems that over the first year, as the trauma is processed and the mothers' battle with existential truths progresses, they become better able to accept the randomness of their experience and can start to ease their sense of responsibility.

6.4 The Horror of Loss

Defining birth trauma, Beck (2004a, p.28) explains that “The birthing woman experiences intense fear, loss of control, helplessness and horror”. In the moment of very premature birth the mother experiences the horror of potential death and loss. Despite the evidential truth that death is the natural and inevitable conclusion of all life, the thought of ourselves dissolving into nothingness is too frightening to contemplate. In turn, it introduces the question of what purpose our life holds if it all ends in nothingness. To avoid this existential pain we spend much of our life’s energy building the illusion of a buffer between ourselves and death, one which we are content to believe in and trust, creating a surprisingly successful false sense of security, control and comfort. This buffer can be so convincing that it is only when we come face to face with death and loss that we internalise the knowledge that death, loss, and chance are inescapable, bringing intense shock and horror.

I could sense how intensely vulnerable my participants felt to losing their baby. This existential terror hung over them throughout their baby’s first year and for some this cloud still follows them, although less prominently. The fear of loss influenced all areas of their mothering, particularly during the early months. Vicky (10:21) vividly describes the period following hospital discharge as a “*second set of horror*”; similarly, Pam (5:28) describes it as “*a whole second cycle of scared*”. All the mothers described an intense fear that their baby might die. They had emerged from a period of weeks during which sudden decline and death of the baby was part of their daily concerns. The repercussions of this precarious start had not subsided and as they described, their babies would stop breathing for seconds at a time, launching them into survival mode,

poised and ready to resuscitate their baby. These fears were based on realistic medical concerns related to premature birth - premature babies are more susceptible to respiratory complications, as well as illness and infection in their first years of life (Gunter, 2010; Blencowe 2013; Jefferies 2014).

However, the phenomenological nature of this study really draws out the existential element of this fear. As mentioned, the mothers had faced the reality of the possible death of their child over a prolonged period. Hearing their experiences of the first few weeks it seems that in an effort of self-preservation they had prepared themselves to face the worst outcome by internalising the mortality of their baby and accepting the real possibility of losing them. Once engaged in this process, it became difficult for the mothers to forget their baby's mortality, even after they were grown and healthy: *"And then of course there's kind of, you've nearly lost him so you're just kind of waiting, to make sure that you're actually gonna keep him"* (Vicky, 12:22). The mothers struggled to develop trust in their baby's resilience and ability to survive out in the world unaided.

Relating to this fear, the mothers described the removal of the hospital monitors as a significant loss. The monitor was a direct line of communication, informing them how their baby's body was working. Without the monitor they had no tangible confirmation that everything was okay and no warning to alert them to any danger. After discharge, the mothers seemed to assume the role of monitor, closely watching and checking the baby to make sure it was okay and constantly looking for signs of danger and death. The mothers were unable to trust that their baby could function and survive independently. This difficulty was another result of their existential shattering, and developing this trust was a challenge for them over the first year. Previous research

reports similar findings, with mothers missing the reassurance of the monitor to indicate any decline in the baby's condition (Raines, 2013; Galeano, Marín & Semenic, 2017; Granero-Molina et al., 2019).

The mothers in my study were also concerned about their baby's susceptibility to illness and infection. Although some laughed at themselves for this vigilance, evidence suggests a higher risk to premature babies for both illness and developmental issues related to essential medication in the early weeks in the NICU (Gunter, 2010; Blencowe et al., 2013; Cohen 2018). Granero-Molina et al. (2019) also found that mothers worry about germs and cleanliness when bringing their extremely premature infant home. When the mothers explained their conflicting emotions of fear and laughter at themselves I got a strong sense of how difficult it was to reconcile their heightened existential awareness with their efforts to recover and build a normal day-to-day life. This is strongly expressed by Anita, who wanted so much to take her baby on outings but was so overwhelmed by her heightened sense of existential vulnerability that she felt paralysed and often ended up cancelling.

Previous research shows similar findings, with mothers displaying intense fear that their baby might die (Golish and Powell 2003; Gunter, 2010; Gonzales and Espitia 2014; Spinelli et al., 2015; Granero-Molina et al., 2019). They also feared causing their baby harm by touching or holding it in the wrong way (Gonzales and Espitia, 2014; Spinelli, 2015). Granero-Molina et al. (2019) found that mothers worry about infection and cleanliness when bringing their extremely premature infant home. Later studies show that one of these mothers' main concerns about discharge was missing a change in their baby's condition and the baby's health deteriorating (Raines; 2013; Galeano, Marín & Semenic, 2017; Granero-Molina et al., 2019). This supports research by Hall

et al. (2013), who found that after premature birth mothers find themselves ‘in the space of life and death’ (Hall et al., 2013, p. 110).

The heightened awareness of existential vulnerability also affected the mothers’ ability to bond with their baby. In the NICU the uncertainty of their baby’s survival was painfully salient, yet mothers are encouraged to bond with their baby, to develop love for it, care for it and imagine that one day it will come home. Cooper (2003) discusses these paradoxes that we are forced to face and the great challenge of recognising and accepting the finitude of life, while learning to risk engaging with life and with others in the face of this reality. As Cooper (2003) suggests, the outcome of this internal clash can result in fear, anxiety, and helplessness in the mother.

Understanding this emotional conflict, it is unsurprising that previous research shows that parental stress in the early days after birth affects the amount of interaction between mother and baby in both preterm and full-term cases (Bener, 2013; Hagen, Iversen and Svindseth, 2016; Ionio et al., 2017). This indicates that parents of premature babies may interact less with their babies, suggesting a reluctance to bond and become emotionally attached. When the baby is well enough to be discharged there is joy on this long-awaited day, but also anxiety and fear of what lies ahead. Vicky describes her anxieties in the early stages after homecoming: “You’ve nearly lost him so you’re just kind of waiting, to make sure that you’re actually gonna keep him.” (Vicky, 12:22). Cooper (2003, p. 23) would argue that this anxiety derives from our drive to push against ‘unmovable boundaries such as death and chance’. The inner conflict between our knowledge of the absolute and our instinct to fight it creates feelings of anxiety, fear, and helplessness.

The nature of the extended stages of a baby's development means that there is no immediate resolution to fears about a very premature baby's development. The state of anxiety and increased vigilance is therefore prolonged. This complements research by Dicenza (2012), who also found that the stress and anxiety of parents of premature babies was prolonged after hospital discharge. My research adds to findings that highlight the extended time premature babies take to reach milestones due to the prematurity which generates a feeling of inevitable delay and a sense of urgency and anxiety about reaching developmental milestones (Dicenza, 2012; Gonzales and Serrano, 2012; Whittingham et al., 2014; Evans et al., 2017; Aloysius et al., 2018; Granero-Molina et al., 2019). It is not surprising therefore, that when looking at the year following discharge, mothers were still struggling to bond with their baby, or that bonding was a slow process. Their references to the present show how their understanding and meaning-making from their experiences is ever-growing, and that their relationships with their children are continuously developing. As Van Deurzen (2015) highlights, we are always aware of our future death and our challenge is to find a meaningful way to live our lives until that point (Van Deurzen and Adams, 2015).

6.4.1 Acknowledging intangible loss

One of the most profound elements that emerged from my interaction with my participants was the overarching feeling of deep loss. I sensed this loss through their facial expressions and deep sighs, even when their words were searching for meaning and positivity. They spoke about their losses in different ways, but they all seemed to struggle to articulate exactly what it was they had lost. Reflecting on their experiences in the first year after birth, Beth and Heather speak of feeling as if something had been 'taken away' from them; Beth and Pam both explained how they felt '*cheated'*, but all participants struggled to pinpoint exactly what it was they had lost (Beth, 11:15; Pam,

13:17). When they did arrive at the reasons for their feelings, they immediately questioned their validity.

The losses identified all related to highly valued experiences, such as a normal healthy birth, holding and meeting their baby immediately after birth, and a healthy start to life for their baby. They also spoke about losing the experience of the final trimester of pregnancy, which was dismissed as a trivial loss; yet the literature shows what an important emotional role that trimester can play for the mother, not to mention its physical importance for the baby (Kristeva, 1986a; de Beauvoir, 1997; Butterfield, 2010). However, the interviews made it clear that the frame of reference for the mothers was the horror of the NICU, and despite touching on the value of what they had lost, they could only view these elements relative to the horrors they had faced and witnessed. Despite what they had been through, they are aware it could have been worse and a sense of existential gratitude keeps them afloat. There is value in this perspective, and existential gratitude plays an important role in mental wellbeing, but it also seems to have stood in the way of allowing them to acknowledge their pain and grieve their loss.

Despite their outward, intellectual rationalisation of the experience of premature childbirth, the intensity of the mothers' loss emerged in their reflections on their experiences during the first year after birth. Nicole spoke of having to mourn the death of the child she had imagined. She mentioned all the expectations she had had for her pregnancy, the birth, and her unborn child, and she described how at the moment of birth it was as if that child had died. She described being unable to hope or expect anything because everything became completely unknown. A further loss was the ability to hope for a positive outcome. As can be common when faced with existential

challenges such as death and illness, her fantasy that everything would be okay in the end had been shattered. She could not conceptualise anything to bond with and was left waiting in the limbo of not knowing. Nicole's powerful account recalls Spinelli's study and his description of standing in the space between life and death (Spinelli et al., 2015). Mothers of very premature babies are left paralysed with fear, in a situation in which it is impossible to make an educated choice of how to respond. They must remain in the space of the unknown, which can be difficult to bear.

Angela referred to her feelings during that first year as '*a strained happiness'* (Angela, 3:18). The fact that her experience could not fully meet her previous hopes and expectations meant that she could not feel a complete happiness. It was a happiness with a little bit missing and therefore inflected with a sense of loss. However, following her struggle to conceive she was determined to enjoy her first year and to be happy. She speaks of a '*cognitive dissonance*', whereby she ignored the sense of loss and pretended to herself that she was happy. However, now, a few years on and looking back, there was sadness in her voice as she acknowledged how difficult her first year had been, and her sense of longing for what she had hoped it would be.

These findings are supported by very similar accounts referred to in published research that commonly depicts this ongoing emotional dichotomy in mothers of very premature babies who swing between pressure to feel joy about the birth of their child and a host of negative emotions related to the early birth including loss, fear and anxiety (Golish and Powell, 2003; Hall et al; 2015; Spinelli et al., 2015; Toral-Lopez et al., 2016).

6.4.2 The ontological implications of loss

6.4.2.1 Ontological anxiety

The mothers in my study learned through their trauma that the horror of loss is always present and always possible. Speaking to my participants, a strong sense emerged that the fear and anxiety brought on by their experience had spilled over into a generalised worry and anxiety that they do not remember feeling before. Facing the sudden trauma of early birth highlighted the reality of the unpredictable nature of life; as Van Deurzen explains, "When life is not taken for granted, existential anxiety is experienced" (Van Deurzen, 2002, p. 35). In light of this theory, it makes sense that after the trauma of premature birth, mothers not only experience a fear of their baby dying, but also a wider existential crisis, questioning their own resilience, purpose, safety and meaning in life.

It can therefore be said that the new mother of a premature baby experiences both ontic and ontological anxiety (Tillich, 1980; Van Deurzen, 2002). She is faced with the tangible horror of her tiny, fragile, medically dependent baby, a horror which is physically and biologically based, and she is also overwhelmed by the sudden change of life as she knows it and understands how to relate to it. Understanding it from this perspective validates the fears and anxieties mothers faced in adjusting back to their everyday routine.

6.4.2.2 Living with embodied trauma

Merleau-Ponty (2012) suggests that the body stores memories of physiological experiences that influence the way we engage with the world. Mothers who have given birth very prematurely have experienced their body as failing in its primary physiological task. The mothers felt let down by their body's failure to perform the seemingly automatic and basic process of childbirth, introducing an awareness of their physiological fragility and mortality. They must now engage with the world and with their baby in and through a body that they experience as unreliable and dangerous. According to Merleau-Ponty (2012), this embodied experience can foster an anxiety and fear that will affect their future engagement with the world. My participant Nicole gives an eloquently description of how this affected her when, months into the first year, she began to imagine that people were following her and trying to kidnap her child. Her experience of envisioning her child being abducted and the possibility of losing him stayed with her and continued to manifest itself in different fears of losing her child (Nicole, 13:2).

My participants describe a loss of trust that their body would function as it should and I detected a sense of powerlessness or even defeat by a body that was unpredictable and uncontrollable. This loss of trust in the body created a new layer of fear and anxiety in the mothers, a fear of inhabiting a body that could fail them at any time. This concurs with research by Spinelli et al. (2015), which shows that a mother can feel confused by her healthy body's failure to carry a pregnancy to term. The results show how a mother can view her body as an unsafe, risky, and dangerous place (Spinelli et al., 2015). This can also exacerbate the inability to trust in the robustness of the baby's body and ability to survive without support (Golish and Powell, 2003; Hall et al; 2015; Raines, 2015; Spinelli et al., 2015).

This study has shown that mothers of very premature babies experience loss in many different areas. It also highlights how subjective the concept of loss can be. Participants describe different objects of loss, and the experience of this loss was individual and personal for each mother. My findings make it clear that all areas of loss can have ontological implications and this is important in considering timeframes for emotional support. For example, research studies address the loss of control over the baby's medical care and the difficulties this poses for parents during their baby's hospitalisation in the NICU (Neri et al., 201; Ionio et al., 2017; Hall et al., 2017). Spinelli et al. (2015) refer to this as the loss of the parental role. Supporting this notion, other studies have shown how the active involvement of mothers in the care of the baby on the NICU can have a positive outcome for bonding and parental self-efficacy (Smith, 2013; Ingram et al., 2016). My research takes these important findings a step further and explores not only how difficult this loss of control is for the mother in hospital, but how it has long-term implications for the development of the mothering identity and the mother-baby bond.

These findings may also be important for understanding the fear and lack of confidence felt by mothers regarding caring for their infants at home after discharge. After struggling to accept that medical staff know best how to care for the baby, the mothers then need to backtrack on this discourse and learn to believe that they are capable of taking care of their baby themselves. This was the common experience of all the mothers: Eleanor wanted to call the NICU to ask how her baby should sleep, while Anita and Beth became terrified when their baby cried and felt that they would be unable to comfort them.

Immersed in these emotive narratives, it became clear to me that the mothers' horror of loss is really an intensified state of the existential terror we all experience every day. This is what makes it so difficult to recover from. There is no confirmation that the horror is over, only that this particular horror has passed for now. Existential awareness brings our constant vulnerability to the fore, spreading the anxiety and fear to everything, because there is now an acute awareness that everything can go wrong, drawing ontological anxiety into the everyday.

6.5 The terror of isolation

After many weeks in the insulated, surreal world of the hospital NICU, my participants were suddenly thrown into the world as mothers of a tiny, fragile, completely dependent baby. All the mothers remember feeling completely alone. The context of the loneliness was individual to each case, with some feeling physically alone and far from family, while others felt emotionally alone as their experiences differed from those of others around them. Furthermore, all the mothers felt medically alone. They could not themselves make sense of the trauma and the journey they had just travelled, and they now faced a world they felt could not possibly relate to what they had been through. Their journey had exposed them to the terrifying reality of existential vulnerability. Although they had come through their trauma, they had seen a truth that was impossible to turn back from. The rest of the world does not want to see or think about that truth and they were alone in their existential authenticity.

Yalom (1980) and Bugental (1981) introduced loneliness and isolation as a third given of existence. Yalom (1981, p.353) argues that the individual is inexorably alone and particularly, alone in his responsibility for directing his own life. He claims that there

will always be an unbridgeable gap between one individual and another. For example, even when two people undergo the exact same event, it is impossible for them to experience it in exactly the same way; there will always be a physical and existential gap between one person and any other being. Bugental (1981) suggests that when one becomes aware of the reality of this separateness it introduces intense fears of anxiety and despair. Yalom (1980) and Bugental (1981) suggest that these fears are so strong that at an unconscious level we put all sorts of defense mechanisms in place to combat them and to try to close the gap as best we can. According to Yalom (1980) and Bugenthal (1981), this is one of the reasons we are driven to merge with specific groups or other individuals, or in some instances, to make desperate attempts to be noticed and approved by others. By joining with others, we deceive ourselves that we are not alone and pretend to ourselves that we are not alone with our ultimate responsibility.

However, although possibly driven by fear of isolation, connecting to others is not a negative trait and existential philosophy also highlights that our experience of being in the world is always in relation to others; building meaningful relationships with others plays an essential part in what Merleau-Ponty (2012) calls ‘being towards the world’, forming our identities and creating joy in our lives (Heidegger, 1996; Sartre, 2003; Merleau-Ponty; 2018; Van Deurzen, 2002). These social interactions create a much-needed sense of belonging and group identity, in which people can offer mutual validation of value choices, mutual support, and empathy. New mothers may join new mothers’ groups that offer a sense of approval and belonging.

6.5.1 Isolation and support

However, the mothers in my study feel so different in so many aspects of their experience that they felt unable to connect anywhere in this way. From a practical perspective, although the baby was well enough for discharge, the mothers felt that the provisions of the general postnatal support system were insufficient for their baby's needs. They no longer belonged in the NICU, but nor did they quite belong in the community medical system, and lacking access to this support caused fear and desperation. The mothers painfully recall that when they did try to access support their concerns were dismissed and attributed to normal new mother's anxiety, so that they were often left 'floundering' (Nicole, 10:23). This fits with recent statistics published by Bliss, showing that 45% of parents lacked access to psychological support when they needed it post discharge (Bliss, 2020).

Two of my participants, who were offered continued neonatal support after discharge, reported feeling less isolated and more supported than those who did not receive such continued support. This also supports the findings of Tomlin, Deloian and Wollesen (2016); Galeano, Marín and Semenic, (2017); Ericson et al., (2018) and Evans et al., (2017), that continued nursing support at home had a positive impact on coping and combatted feelings of isolation. While there has been a strong focus by the NHS on reforming and improving support services for new mothers and babies in the weeks after birth, the mothers in my study expressly found the community midwifery support post discharge to be lacking, particularly regarding their own mental health. This was a surprise finding as the role of the midwife is specifically to support the woman. There was a unanimous feeling that the community health visitors needed training on very premature birth and the resultant effects for both baby and mother. This suggests that

although there may be a move to improve services in general, the particular needs of this minority group of mothers are still not being met. This relates to existing findings that emphasise the importance of community support by specialist nurses and midwives who have received specific training in caring for premature infants (Whittingham et al., 2014; Tomlin, 2016; Osorio Galeano, Ochoa Marín & Semenic, 2017; Evans et al., 2017; Ericson et al., 2018; Granero-Molina et al., 2019).

It is possible that given the financial constraints on health service provision, NHS policy forbids or prevents the kind of support my participants sought. The problem is not necessarily a lack of training on the part of the midwives; rather, it may be that maternity services are not organized in a way that allows mothers of prematurely born babies to access the help they need and which community health visitors might otherwise be pleased and qualified to provide. The problem therefore seems to be managerial, in that mothers who return home after NICU may not qualify for the kind of support automatically provided to those who return home immediately after the birth, since their babies will be many weeks older, and therefore assumed not to be in need of specialist care.

My participants gave birth 3-5 years prior to these interviews and it is possible that community services may have further improved since this point. However, recent Bliss statistics show that no nation in the UK is achieving national standards for psychological support in neonatal units, suggesting that post-discharge support remains as severely lacking as in the past (Bliss, 2020).

All the mothers in my study experienced a dramatic drop in support as soon as they

brought their babies home. Lack of understanding from friends and family made it difficult to connect to them, and preoccupation with protecting their child drew them away from social interaction. Published research findings varied on this issue. Hall et al. (2013) found that mothers felt friends and family were supportive and stepped in when the baby came home. Golish and Powell (2003) found similar results, with participants mostly finding friends and family supportive, while conversely, Granero-Molina et al. (2019) found that mothers were preoccupied with worries about their baby's health which pulled them away from friends and social life. There are evidently too many variables – social, regional, and cultural – to make generalization possible on this topic.

Golish and Powell (2003) reported that when their participants felt misunderstood or distanced from friends and family, they took the active approach of educating others about prematurity in an effort to close the gap. However, this was not always successful. By contrast, most of my participants seemed to withdraw from these situations of potential connection, resulting in heightened feelings of loneliness and isolation.

Gonzales and Espitia (2014) showed that although family were around, they were so afraid to touch or care for the baby due to its fragility that the mother still felt alone in her responsibility to care for the baby. This matches my findings: even when family and friends were around, most of the mothers still felt emotionally alone. In the less common instances where support was available within the mother's community, such as support from other premature mothers, or help with meals, lifts to the hospital or childcare, the feeling of isolation was reduced.

6.5.2 The need to belong

The mothers did not feel a sense of belonging among other mothers, who had given birth at full term, because they felt they could not possibly relate to their birth experience or their journey as a mother. They also felt that their baby was different, either because it looked smaller and different or because it was at a different developmental stage to that of other babies of the same age. They were sure others saw their baby the same way, causing them to feel defensive and protective. Despite making efforts to join social groups such as NCT groups, baby massage or mother and baby groups, my participants continued to feel set apart from the other mothers.

Referring to the ideas of Yalom (1980) and Bugenthal (1981) on the subject of loneliness and isolation, the mothers' feeling of separateness obstructs their ability to merge with the new mother cohort and leaves them without the sense of belonging and approval they crave. This leaves mothers feeling alone and isolated and, as Yalom (1980) and Bugental (1981) suggest, introduces a new layer of anxiety about their own belonging and may threaten their sense of being loved and accepted by others.

Stern, as explained by Spinelli et al. (2015), speaks about learning from other mothers, particularly one's own mother, to help build one's mothering identity (Stern, 1995). Current research suggests that when the baby and the mothering experience is so different from that of others around the mother, this natural learning process becomes stunted, resulting in mothers feeling left to grapple in the dark to figure everything out on their own. However, when participants met other mothers of premature babies with similar experiences, a similar process seemed to kick in, by which they could use these

other mothers as a point of reference to build their own mothering identity. One of my participants commented that peer support from other mothers of premature babies made a significant difference to her experience. Sharing and hearing stories from other mothers helped to normalize and validate their experiences.

Research has also found that NICU mothers formed relationships with one another and that these friendships were important for support, validation and approval of their mothering skills (Golish and Powell, 2003; Gonzales and Espitia, 2014; Levick et al., 2014; Hall et al., 2015; Spinelli et al., 2015). My research adds to this consensus by showing how relationships with other NICU mothers remain necessary and valuable months and even years after discharge. Consulting with other premature mothers gave them an opportunity for reassurance and encouragement that they were doing the right things and helped them to establish their identity as mothers. This supports findings of recent phenomenological exploratory research by Granero-Molina et al. (2019), who found that peer support was highly valued by mothers 12 months after discharge. Arnold-Baker's (2015) study shows that this is similar to the path of a full-term mother's development of her mothering identity.

6.5.3 Belonging in the NICU

All the mothers spontaneously shared their desperation to remain in touch with the staff on the NICU where their baby had been hospitalised, creating a strong common theme of attachment to the NICU post discharge. There is a sense of great comfort in receiving acknowledgement from those who had borne witness to their traumatic journey. This new finding highlights a different need in mothers of premature babies which has not been addressed in previous research. In the depths of their isolation,

when feeling set apart from and misunderstood by most people around them in the outside world, the NICU was a place where staff and other NICU parents truly understood the complexity of their journey, the emotional experience they had been through and its aftermath. The mothers are consistently drawn to both the staff and parents they met in the NICU and it is there that they felt a sense of belonging with those who understood and acknowledged their journey without needing any explanation.

Listening to the mothers talk about the NICU, a sense of calm and comfort was apparent. They were thrown into a terrifying abyss of the unknown, but the NICU staff had trodden this path many times before and could hold up a beacon in their darkness, explaining what to expect and offering the reassurance they so desperately craved. The NICU staff knew how to handle the disaster they faced and worked tirelessly to nurse their baby to health. I can relate to their reflection that it is difficult to quantify the level of gratitude felt for the people who care for what is most precious to you when you are completely unequipped to do anything about it yourself. The mothers speak about how proud they are of their babies' accomplishments and wanted to show off their babies to celebrate how far they had come. It seems that the NICU is where they felt that this longing could be truly appreciated.

When they went home alone, facing a new journey of horror and unpredictability, it makes sense that they longed for this guidance and support, both medically and practically, particularly in the first few weeks. These findings contrast with some literature that suggests that parents were happy and relieved to be away from the NICU environment (Golish and Powell, 2003; González and Espitia, 2014), but it supports a number of other newer studies that report mothers needing advice and

information from the NICU specialists regarding their baby's care (Whittingham et al., 2014; Tomlin, 2016; Galeano, Marín & Semenic, 2017; Evans et al., 2017; Ericson et al., 2018; Granero-Molina et al., 2019. As noted above, there are too many variables of temperament and circumstance to make generalization feasible.

While the NICU provides a feeling of comfort and support, it is accompanied by the painful realization that in reality this is not the kind of support mothers would have needed if the birth had proceeded normally. Although the NICU has been identified here as an opportunity for belonging and group support, it actually exacerbates the experience of isolation because it is out of reach once mothers have returned home. The resolution to this came through seeking out relationships with other mothers of premature babies, either online or across the community. The mothers eventually found their sense of belonging through peer support and they continue to nurture these valuable relationships.

My findings are important in light of research that highlights the importance of ongoing NICU or specialist support services after hospital discharge. My participants' longing for a connection with the NICU supports the outcomes of these studies, which show a positive correlation between continued outpatient support and coping as well as reduced anxiety in parents of premature infants (Forsythe and Willis, 2008; Cantle, 2013; Landsem et al, 2014; Beresford, 2015; Tomlin, Deloian & Wollesen, 2016). My research adds to this by suggesting that elements of acknowledgement and validation of the trauma are added positive outcomes of continued support from the NICU and can potentially add to mothers' emotional wellbeing.

6.6 Post traumatic growth – A new existentially authentic world view

6.6.1 Picking up the shattered pieces

At the time of hospital discharge the mothers and their growing babies began to edge out of the danger zone and slowly emerge out of their trauma back into the outside world. While it seemed to them that the world as they knew it had stopped completely with the birth of their baby, outside the NICU the world had continued as if nothing had changed. Since childhood these mothers, like all of us, had used their experiences, relationships and acquired knowledge to create a blueprint for how to navigate life and relate to the world around them. During the isolated journey of their trauma their beliefs, faith, and expectations of the world had been shattered and they emerged to face a life in which their blueprint was suddenly useless, as if they were sitting alone surrounded by a pile of useless shards of glass. However, they were not alone - they also had a very fragile baby who depended completely on them for both physical and emotional care.

All the mothers explained that they could not look at the world in the same way again. This change introduced some positive elements of growth and gratitude, but also the elements of fear and isolation explored above. Heather described how her perspective on life had been altered and how this made her both fearful of how quickly things could change, but also more grateful for the simpler and happier times (Heather, 12:22). Similarly, Nicole explained that she hadn't previously realised how fragile life was, bringing her a sense of existential gratitude (17:29). Heather speaks enviously about an innocence other mothers have that she feels her trauma took from her, and while her own awareness brings gratitude and existential wisdom, she feels the weight of this awareness and envies those who have not been forced to face these truths.

As an existential psychotherapist I could sense that the mothers had reached a state of existential clarity. Their existential awakening was painful and shocking, but they could no longer return to the safety of their denial even when it seemed so inviting. They knew that they needed to stay true to their new knowledge and live in an existentially authentic way; however, they had no idea how to synthesise all the different pieces they were starting to recognise. It is here that existential psychotherapy could provide a pathway for these mothers to explore and make sense of their experiences, allowing them to process their trauma, picking up their shattered pieces and creating a new blueprint that incorporates their new authentic values and helps them figure out how to live in a new and fulfilling, but authentic way.

The mothers in my study felt so confused and alone in their experience that it didn't occur to them that professional support might be relevant to them and could help them to process their experiences. On the rare occasion that a mother did try to access support they were pushed away and denied the validation they deserved. There is evidence from my research and that of others that a lot of support is provided during the hospital stay and even the first few weeks after discharge. However, my findings show there is a delay in the processing of the trauma and that it is only months into the first year that mothers remember being able to start piecing together and beginning to make sense of their experiences. This is a new and important finding as it is precisely during this period that all emotional support has been withdrawn. This is in line with current research on full-term mothers that has shown that mothers begin to make sense of their experiences only towards the end of the first year after the birth (Arnold-Baker, 2015).

It is encouraging to see that strong efforts have been made by NICE and the NHS to emphasise the challenges of the premature birth experience and to make provision for very premature babies and their mothers after hospital discharge. However, there is unfortunately still a gap in the provision of monitoring and support for the mental health of mothers of very premature babies. The NICE guidelines focus mainly on the follow-up of the baby, with minimal mention of the mother's needs. While the NHS has put processes in place for assessing the mental health needs of mothers after premature birth, this is available only for up to 8 weeks post birth and does not cover the post discharge period (NICE, 2015; NICE, 2017; NHS, 2009). My study shows that the challenges these mothers face extend far beyond 8 weeks post birth and that it is only much later that they may be ready to engage with emotional support. As Pam remarked, *"It was only . . . around the six months stage, that it sort of hit me"* (Pam, 9:10). These policy changes are certainly reassuring but it seems it will take some time before they filter down into community services and practical change begins to take place. The unfortunate financial and human costs of the current pandemic on the NHS make it sadly unlikely that we will see any improvement in service in the near future.

6.6.2 The role of therapy. Building a mosaic

All the mothers in my study felt that therapy would have been helpful in the first year after hospital discharge. Four of them actively pursued therapy from their NHS provider when they reached a point at which they felt they could no longer continue in their current state. Yet both Vicky and Nicole were turned away and received no support. Both were able to access therapy through other channels but not all mothers would have the ability or the resilience to do the same. They both reported finding

therapy very helpful and that it enabled them to cope. The mothers who did not pursue therapy felt that in hindsight it would have been helpful and that it had probably been necessary though they had not realised it at the time.

These are new findings as the benefits of therapy for mothers of premature babies in the first year after discharge have not previously been explored. However, these findings do support previous research showing that that mothers on the NICU had found therapy during the NICU stay helpful and that they had expressed a wish to continue therapy after hospital discharge (Forsythe and Willis, 2008; Parker, 2011; Landsem et al., 2014; Levick et al., 2014; Hall et al., 2015). Recent research by Granero-Molina et al. (2019) also highlights the need for emotional support in the first year after hospital.

Despite these clear findings, it is always important to keep the individual experience at the fore. For example, Angela expressed a very different point of view. She felt that her cognitive dissonance and determination to be 'okay' during the first year was a defence mechanism that had helped her survive that first year. She believed that if someone had suggested to her that everything might not be okay or that it might have been a hard time for her, she would have probably rejected the support in order to maintain and defend her coping mechanism. She also confided that thinking back to that time, if she had perhaps engaged with the reality of the situation she might have collapsed emotionally altogether and been unable to cope at all. Angela's perspective was an unexpected finding that distinguishes her experience from that of my other participants and is not anticipated by anything in previous research. This finding is important because it highlights the individuality of each experience. This individuality makes generalization all the more difficult but since deriving general principles is not

an aim of IPA, it is not a problem for the purpose of my research. Despite the importance of the common themes, outlying opinions are important reminders to consider the uniqueness of every individual's experience and the unique emotional needs of every client.

Those of my participants who had expressed a need for therapy stressed the importance of being supported by a professional with knowledge and understanding of premature birth and the NICU experience. This finding supports previous research showing that mothers felt that post-discharge support should be provided by professionals with specialist knowledge of premature birth and the NICU experience (Tomlin, Deloian & Wollesen, 2016; Evans et al., 2017; Aloysius et al., 2018). This draws us back to the need for validation of their experiences and bearing witness to the trauma discussed earlier in relation to the connection with the NICU. Again, I got a strong sense that someone who hadn't been through the experience, or at least thoroughly researched it, would be unable to truly empathise with them.

My findings make it clear that after their existential shattering, new mothers of very premature babies face the challenge of re-evaluating their sense of self and their understanding of what it means to them to be in the world. As Heidegger (1996) emphasises, although we are thrown into undesirable circumstances, we have a choice as to how to respond to these circumstances, the meaning we create, and the way we can then move forward. While this can prove challenging and confusing, it provides an opportunity for the development of new perspectives and greater self-awareness. Existential therapy could give these mothers an opportunity to work through their trauma and provide a space for them to explore and make sense of their

experiences. With its focus on the four dimensions of existence, existential therapy can transcend the client's inner world and help them address their challenges in the context of their personal, physical, social, and spiritual worlds (Van Deurzen, 2010). This can help address their sense of isolation and support them in building fulfilling relationships despite their deeply personal challenges.

Existential therapy is therefore well placed to address these experiences and help individuals navigate a way forward that is both fulfilling and existentially authentic (May, 1950; Tillich, 1980; Yalom, 1981; Van Deurzen and Adams, 2015). Existential therapy can guide them in synthesising their new existential understanding with their core values and beliefs, helping them collect the shattered pieces and reassemble them in new and alternative ways, combining the diverse elements into a meaningful mosaic. This existential exploration can help them create fulfilling and authentic ways of being and relating to the world (Van Deurzen and Adams, 2015).

7. Conclusion

7.1 Summary of findings

This research has achieved it aims by capturing an emotive, phenomenological understanding of mothering a very premature baby in the first year after hospital discharge. The findings show that this is a terrifying and lonely journey, strongly impacted by the initial trauma of the very premature birth and NICU hospitalisation. My participants clearly faced multiple existential challenges and their trauma had far-reaching consequences. This phenomenological study of the period after homecoming is an important extension to existing research, which is mainly focused on parenting within the NICU environment and parents' needs and expectations during the transition home.

Seven superordinate themes emerged from the data: 'The second set of horror; 'The isolation of limbo'; 'Attachment to the NICU'; Feeling like a mother came later'; 'Bonding in the shadow of the threat of loss'; 'Mourning an intangible loss' and 'Mothering in the wake of trauma'. These themes capture how the trauma of the very premature birth and the NICU experience influenced the way these women were able to relate to their babies, care for them, bond with them, and develop their identity as a mother.

The inherent existential nature of these themes stood out boldly and existential concepts were applied to gain an understanding of the mothers' emotional state during these months. Concepts explored included existential shattering; the meaning of being a mother; the horror of loss; the terror of isolation and the importance and comfort of

belonging. The role of emotional support was also explored from an existential perspective. Looking at the themes through an existential lens and exploring them in relation to existential philosophy and existential psychotherapy theory provides a new level of understanding of the experience of this phenomenon.

The findings show that the initial trauma of a very premature birth affected my participants' experience of mothering in the first year after hospital discharge. The mothers were thrown into a confrontation with their existential limitations, calling their understanding of the world as they knew it into question and shattering the framework they had built to interact with the world, including, of course, their expectations of becoming a mother. Discharge from hospital was still only the beginning and they embarked on their mothering journey buried beneath a mountain of remnants of shattered hopes and expectations, without the necessary tools to tackle their new situation. This can be understood as mothering in the aftermath of existential shattering.

Following a numb and bewildered start, the mothers found it hard to connect to their status as a mother and to feel emotionally connected to their baby. They were left wondering what it meant to feel like a mother, or whether they deserved to be mothers. Their prescriptive concept of being a mother did not fit with their traumatic and exceptional circumstances, causing them to feel alone and guilty. The existential approach that motherhood is a more fluid and subjective state than society prescribes can offer more flexibility for mothers facing a complex or traumatic start to mothering to develop their sense of identity in their own individual way. The focus they placed on

reciprocal interaction with the baby supports existential views that reciprocity enhances meaning and connection in relationships.

The mothers felt guilt and responsibility for giving birth early and these feelings spilled over into difficulty trusting their abilities to care for and protect their babies in the following months. Mothering in the first year was described as a terrifying responsibility. Taking care of the baby felt like an endless chore and fears of the baby dying or becoming ill overshadowed any enjoyment of their baby or their status as a new mother. Having faced the horror of potential loss, the world felt like a terrifying place. They could not bring themselves to trust in their baby's ability to survive and connecting to the baby emotionally felt like a great risk. Awareness of their baby's mortality made them acutely aware of their own mortality and of the unpredictability of everything in life, inducing ontological anxiety. The mothers became unable to look at the world without seeing the potential for loss and they felt a further loss of their previous blissful existential naivety.

Isolation emerged as a strong common element of this experience. Not only had they experienced a journey that others could not possibly understand, but they also saw a truth about the world that others wilfully deny. This left them feeling very alone as they tried to navigate a new way of engaging with others and their day-to-day lives. Concerns about the baby's health and development continued for the duration of the first year and beyond and reaching milestones generated intense anxiety in the mothers. This delayed resolution resulted in ongoing despair. A great deal of stress and frustration was attributed to the lack of relevant and accessible medical care. This also contributed to feelings of loneliness and isolation. A strong desire to remain

connected to the NICU was expressed. The NICU was perceived as a source of reliable information and support, providing a sense of belonging and being understood. Peer support from fellow NICU mothers as well as other mothers of premature babies was described as an invaluable source of comfort, and mothers guided and supported each other along their parallel journeys.

The mothers found that as time elapsed and their babies developed and became more robust, they reached a point at which they were able to start to process their trauma and begin to make sense of their experiences. As Hoffman & Vallejos (2018) suggest, the experience of existential shattering also presents an opportunity for existential growth. On reflection, the mothers recognised an altered and although painful, more mature perspective on life. They also expressed deeper gratitude for their children, the simpler joys in life and for life itself. They all expressed a need for emotional support but reported that resources were difficult to access. Those who had reached out for therapy had felt desperately in need, and had found it useful. Of those who did not reach out at the time, most felt with hindsight that support would have been helpful. A need was expressed for better access to therapy from professionally trained therapists with good knowledge of the premature birth and NICU experience.

The findings of this research demonstrate that the challenges of mothering a premature baby continue throughout the first year. These findings provide a closer understanding of the needs of mothers during this time and indicate that focus needs to be placed on the provision of relevant medical and therapeutic support.

7.2 Significance

This study offers rich insight into an unexplored stage of mothering a very premature baby. It highlights that the trauma of the premature birth experience continues to affect mothering and the mother-infant relationship throughout the first year and beyond. Specific significance can be attributed to the new finding that mothers trying to access help feel dismissed. This is important because it indicates a need for mothers' experiences to be acknowledged, so that more accessible avenues of support can be put in place.

The strong attachment to the NICU that emerged from this research is significant as it differs markedly from previous research, which reports a sense of relief at departing from the NICU. This finding can be important for considering the option of continuity of care after discharge, when mothers may experience comfort and support from a continued connection to their NICU staff.

Another significant finding that differs from previous research is the idea of mothering on autopilot. While previous research focuses on the difficulties of caring for a premature baby and the training required, my research highlights a resilience in mothers that enables them to care for their infants despite their emotional distress. It is important to acknowledge this resilience, but also to acknowledge the ongoing demands on the struggling mother and their potential long-term effects.

The 'tiger mother' bond is also a significant finding since it differs from earlier research, which places a focus on the lack of bond between mother and baby. This finding indicates that a strong bond between mother and baby does exist, albeit one that

differs from the bond the mothers had expected to experience, and differs also from the bond described by mothers of full-term babies. This subjective, phenomenological exploration introduces the possibility of a different kind of bond and acknowledges the significance of this bond for both mother and baby.

Previous studies have investigated the importance of therapy and emotional support for parents of premature babies and some have looked at this in relation to the first year after hospital discharge. However, this is the first study to identify a specific need for therapy for mothers of very premature babies born between 28-32 weeks, who have brought home a baby deemed clinically healthy at the time of hospital discharge. This is a significant finding which highlights the need for support and for resources to be put in place to fill this need.

7.3 Reflexivity

As explained in my methodology section, I have been reflexive throughout the design, conduct and analysis of my research. The nature of the Interpretative Phenomenological Analysis research method means that subjective interpretation has played a part in my findings and discussion. My personal experience, preconceived ideas and assumptions have been bracketed, but not ignored and I have examined them in a way that has informed a better understanding of the analytical process and therefore a closer understanding of the data. This has aided in striking a balance between phenomenology and insightful interpretation, while keeping my interpretation grounded in the text.

As the mother of a daughter born at 29 weeks I have my own memories, thoughts and feelings about this experience. As Merleau-Ponty (2012) suggests, I remained respectful of the fact that that although I may be able to empathise with this experience, I can never understand the phenomenon exactly as another has experienced it. Approaching the interviews and the data with an open and curious mind-set helped me to keep the analysis grounded in the text. I have remained aware of inter-relational aspects of the research process and this awareness has helped to minimise any possible effects on the analysis of the data. Writing in my research journal throughout the research process has assisted with this.

A considerable body of literature was reviewed in preparation for this study. I was mindful to minimise any biases that had developed from reading earlier findings. This was helped by the fact that this study takes a new perspective in a different timeframe. Some of my findings echoed those of previous research, such as fear of the baby dying and feeling unskilled and unprepared. However, the commonality of these findings can be attributed to the nature of the experience. These common factors were balanced by surprising new findings that oppose some of the previous findings, such as the feelings of attachment to the NICU, the 'tiger mother' bond and the slow process of coming to feel like a mother, which shed new light on the experience.

Due to the nature of the research method and the process of analysis, it was inevitable that the discussion would also contain elements of my own interpretation. As mentioned in my methodology section, I felt that the participants were placing a certain amount of hope and trust in me as the researcher, and I felt a great responsibility to

carry their voices forward as accurately as possible. Constant reflection on these elements helped me keep the discussion closely related to the text.

7.4 Limitations

As with most research, this study is not without limitations. Upon reflection, the research invitation was sent out to the database of a support organisation indicating that I have selected participants who had already reached out for support. Arguably, had the recruitment net been cast wider I would have achieved different results. However, 2 of my participants were recruited via word-of-mouth, thereby achieving a better balance, given that two out of eight participants constitute 25% of the entire sample.

The sample number of 8 may be considered small. However, the purpose of this study was to gain an in-depth understanding of experience and for this purpose the sample size was adequate. Further research encompassing a wider group of mothers or participants selected through a different source might possibly yield different results.

The interviews took place in different locations and each location had a different atmosphere. 4 interviews were held in the private meeting room of a building in town, which could potentially have created an impersonal, corporate atmosphere that did not quite suit the nature of the meeting. The other interviews took place in library meeting rooms and counselling rooms. The different context of the interviews may have affected participants' comfort and openness; arguably, a more similar type of venue in each location could have provided a more equal starting point for each interview.

However, the interview results show no evidence that the differences in location had affected the results in any way.

7.5 Validity

Validity has been addressed in my methodology section, which demonstrated how I have applied the principles set out by Yardley (2000) throughout my research process. As noted there, Yardley's (2000) two remaining principles will now be discussed.

7.5.1 Transparency and coherence

I have been transparent throughout by clearly explaining my research process and analytic procedure. I have also provided excerpts from participants' transcripts to support both my analysis and discussion. I have endeavoured to present my work in a coherent and understandable way, with the intention of providing the reader with an interesting and informative understanding of my participants' experiences.

7.5.2 Impact and importance

The text makes clear that this is a group of women who would like their voices to be heard and their experiences acknowledged. The research has shown how their experience may be identified as traumatic, and it has highlighted the loneliness and difficulty of this time. The importance of support has been highlighted, as well as the importance of putting measures in place to support the millions of other mothers who will also go through this experience, albeit in their own individual way.

7.6 Implications for further research

This research has indicated that mothering a very premature baby at home after hospital is a new and relatively underexplored area of research. This experience still holds rich and important elements to be explored, for example, what it is like for fathers to parent a premature baby at home or how a very premature birth affects the marital relationship. The mother's relationship with the body that has let her down could also be an important topic of exploration. Seven of my participants were first-time mothers. This led me to wonder how this experience might affect their feelings about having further children, or how they might approach a future pregnancy, another potential area for future research.

Most of my participants were first-time mothers; only Eleanor had an older child. Differences were highlighted between Eleanor's experience and that of the other mothers, which could potentially be attributed to the fact that she was already a mother to a child born at full-term. However, there were also many similarities. A large part of this research focuses on the process of becoming a mother. A woman who is already a mother may therefore have a different experience in that regard. Further research on this topic could investigate whether first-time mothers' experiences of very premature birth differ from that of mothers with older children and could also highlight elements of the experience that may be universal. This could shed further light on the experience of mothering a very premature baby and perhaps also highlight different support needs in different parent groups.

While this research focuses on the specific experience of very premature birth, there are many reasons why a birth may be traumatic or why a baby might need specialist

care on a NICU ward. My research suggests that similar traumas are also likely to present long-term emotional challenges. It would therefore be valuable for research to be undertaken on these mothers, to improve our understanding of their experiences and determine the type of support that should be offered.

7.7 Implications for clinical practice

My findings show that new mothers of very premature babies find the first year after hospital a terrifying, anxious and lonely time. The very early birth is experienced as a trauma and the extended hospital stay has lasting effects on the mother's emotional state and ability to bond with her baby. The findings suggest that due to prolonged shock and trauma during the NICU stay, the mothers do not begin to process the trauma until months later, when the baby's growth and development has stabilised and they are out of immediate danger. This acute fear and anxiety continue until the baby has reached all their developmental milestones, which can take up to 18 months after birth. As my research shows, developmental difficulties are sometimes uncovered during this time.

Despite these challenges, access to both medical and emotional support is reported to be very limited. The horror of the potential loss they have faced and the delay in resolving their fears leaves them floundering alone in their existential terror. These findings clearly indicate that counselling and support from a trained professional during the first year after discharge should be viewed as essential in order to support these mothers' mental health and their relationship with their babies. Current NICE guidelines recommend that mental health assessments should be provided until 8 weeks post birth (NICE, 2017). However, my participants found that they only began

to process their trauma months later. This indicates that the timeframes for checking in with new mothers should be revised to include more check-ins at later points during the first year and at the one-year mark. Furthermore, community health providers need to be aware that these mothers are likely to require emotional support during this extended period, and that referral should be made to the relevant mental-health support services when it is requested.

This research highlights that the challenges these mothers face are inherently existential and that it can be beneficial to process their experiences through existential exploration. Existential therapy's focus on the inescapable limitations of human existence can help these mothers understand the root and meaning of their fear and anxiety (Yalom, 1981). An existential therapist can help mothers find ways to engage with day-to-day life and with their baby, while acknowledging and facing these existential limitations (Cooper, 2003; Van Deurzen, 2002; Van Deurzen and Adams, 2015). Existential therapy's strong focus on meaning-making can help these mothers find meaning in their experiences and make sense of what they have been through, assisting them in processing their trauma and also in finding a new meaningful perspective on their lives (Cooper, 2003; Van Deurzen, 2002).

Existential therapy can also provide a non-judgemental space for these mothers to verbalise and explore their feelings of loss and grief, helping them make sense of their conflicting emotions, providing acknowledgment and validation for their pain and loss within the greater context of their positive outcome (Van Deurzen, 2002; Van Deurzen and Adams, 2015). Addressing feelings of fear, anxiety, and loss can assist mothers in feeling more open to developing a bond with their baby and support them in developing their identity as a mother (Cooper, 2003; Van Deurzen, 2002; Van Deurzen

and Adams, 2015). Feminist existential literature has introduced a more flexible and subjective concept of what it means to be a mother, presenting discourses that could assist women to shape their own individual mothering identity within the context of their personal challenging and complex transition to motherhood (Kristeva, 1987; De Beauvoir; 1997; Butterfield, 2010).

The unusual birth circumstances and transition to mothering sets these mothers apart from mothers of full-term babies and they find it hard to find their place in social settings. They also find their babies' development and physical appearance to be different from that of full-term babies, which causes feelings of stress and anxiety. A focus on the four dimensions of existence can help these women understand their social dimension, thereby helping them navigate their personal relationships and build support systems (Van Deurzen, 2002; Van Deurzen and Adams, 2015; Yalom, 1981). This could help in combatting the loneliness and isolation that were so prevalent for all the mothers.

All the participants benefited from online and face-to-face groups that put them in touch with other mothers of premature babies. This important outcome indicates that support groups for mothers of very premature babies are an important element of support and should be more available. A support group facilitated by a trained existential psychotherapist could provide a supportive space for these mothers to share and explore their experiences, and in so doing, provide support and validation to one another. This research can be useful to counsellors wishing to facilitate these groups, as it gives a rich insight into the needs and wishes of these mothers.

With the incidence of premature birth steadily increasing in tandem with rising survival rates of very premature babies, the number of women mothering these babies in their first year is also rising, creating a growing need for psychological support. This is therefore a phenomenon that parents will want to discuss in therapy and it is arguable that therapists are going to need a better understanding of this experience in order to meet their clients' needs. The findings show that mothers would like therapists and medical practitioners to be more knowledgeable about premature birth and the experience of mothering a premature baby. This research provides a rich understanding of the experience of mothering a premature baby, which can therefore be considered a valuable resource to health professionals, counselling psychologists and the mothers that they will support.

Over and above very premature birth, there are many and varied reasons why a birth may be traumatic or a baby might be admitted to NICU. This research highlights that mothers in any of these traumatic situations are likely to experience long-term emotional repercussions and should be offered support for an extended period of time. Previous research suggests that providing emotional support has proven successful in reducing symptoms of stress, anxiety, and depression (Cantle, 2013; Forsythe and Willis, 2008; Landsem et al., 2014). A reduction in these symptoms is positively correlated to an improvement in mother-infant bonding and relationship as well as better physical and emotional development of the infant overall (Landsem et al. 2014; Mertesacker, 2003). These improvements have also been linked to improved relationships between parents and other siblings and increased spousal concord (Landsem et al., 2014). Intervention in the early stages could therefore prevent future family breakdown and save costs to other family services.

This research is therefore important to counselling psychology as it sheds light on a new and growing phenomenon that is likely to become a common presenting issue in therapy practice. This is also the first study of its kind to include an existential perspective and link these specific emotional challenges to existential psychology theory and practice. This research brings awareness of the needs of a growing minority whose needs need to be highlighted and addressed, and provides insight into this unique mothering experience that could help inform future clinical practice.

8. References

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9. Appendices

9.1 Ethical clearance

9.2 Risk Assessment

Middlesex University Department of Psychology Ethics Committee

Application for Ethical Approval and Risk Assessment

No study may proceed until approval has been granted by an authorised person. For collaborative research with another institution, ethical approval must be obtained from all institutions involved. If you are involved in a project that has already received ethical approval from another committee or that will be seeking approval from another ethics committee please complete form '**Application for Approval of Proposals Previously Approved by another Ethics Committee or to be Approved by another Ethics Committee'**

UG and MSc STUDENTS: Please email the completed form to your supervisor from your University email account (...@live.mdx.ac.uk). Your supervisor will then send your application to the Ethics Committee (Psy.Ethics@mdx.ac.uk). You should NOT email the ethics committee directly.

PhD Students and STAFF: Please email the completed form to Psy.Ethics@mdx.ac.uk from your University email account (...@mdx.ac.uk)

This form consists of 8 sections:

1) Summary of Application and Declaration

2) Ethical questions
3) Research proposal
4) Information sheet
5) Informed consent
6) Debriefing

7) Risk assessment (required if research is to be conducted away from Middlesex University property, otherwise leave this blank. Institutions/locations listed for data collection must match original letters of acceptance)
8) Reviewer's decision and feedback

Once your file including proposal, information sheet, consent form, debriefing and (if necessary) materials and Risk Assessment form is ready, please check the size. For files exceeding 3MB, please email your application to your supervisor using WeTransfer: https://www.wetransfer.com/ this will place your application in cloud storage rather than sending it directly to a specific email account. If you/ your supervisor have confidentiality concerns, please submit a paper copy of your application to the Psychology Office instead of proceeding with the electronic submission.

FOR OFFICE USE ONLY

Application No.:	Click here to enter text.	**Decision:**	Click here to enter text.	**Date:**	Click here to enter a date.

RISK ASSESSMENT *(complete relevant boxes)***:**

Required:	☐ Yes	☐ No	**Signed by:**	☐ Student	☐ Supervisor ☐ Programme Leader

Date: Click here to enter a date.

LETTER/S OF ACCEPTANCE/PERMISSION MATCHING FRA1 (RISK ASSESSMENT) RECEIVED (SPECIFY):

	Date	From	Checked by
All	Click here to enter a date.	Click here to enter text.	☐ Supervisor ☐ Ethics Admin
Part	Click here to enter a date.	Click here to enter text.	☐ Supervisor ☐ Ethics Admin
Part	Click here to enter a date.	Click here to enter text.	☐ Supervisor ☐ Ethics Admin

DBS Certificate(s) Required? *(complete relevant boxes)***:**

DBS certificate required?	Click here to choose an item.	**Seen By:**	Choose an item.
DBS Certificate Number:		**Date DBS Issued:**	Click here to enter a date.

1. Summary of application (researcher to complete)

Title of Proposal:	Using Trauma as a lens to explore the experience of mothering a very premature infant in the first year after hospital discharge.		
Name of Principal Investigator/Supervisor	Dr Charlotte Macgregor		
Name of Student Researcher(s) and student number(s)	Romy Shulman Middlesex Student number: M00475227		
Please click one of the following:			
○ UG Student ◉ PHD/MPHIL Student ○ MSc Student ○ Staff			
Proposed start date	01/07/16	**Proposed end date**	01/07/17
Details of any co-investigators (if applicable) N/A			
1. Name: Click here to enter text.	Organisation: Click here to enter text.	Email: Click here to enter text.	
2. Name: Click here to enter text.	Organisation: Click here to enter text.	Email: Click here to enter text.	

3. Name: Click here to enter text.	Organisation: Click here to enter text.	Email: Click here to enter text.

Topic/Research Area (tick as many as apply)

☐ Social/Psychosocial ☐ Occupational ☐ Forensic ☐ Developmental

☐ Sport & Exercise ☐ Cognition & Emotion ☐ Psychoanalysis ☑ Clinical

☐ Psychophysiological ☐ Health

Methodology (tick as many as apply)

☑ Qualitative ☐ Experimental ☐ Field Experiments ☐ Questionnaire

☐ Observation (humans and non-humans)

☐ Analysis of Existing Data Source/Secondary Data Analysis

1.1	Are there any sensitive elements to this study (delete as appropriate)? *If you are unclear about what this means in relation to your research please discuss with your Supervisor first*	YES
1.2	If the study involves any of the first three groups above, the researcher may need a DBS certificate (Criminal Records Check). PG students are expected to have DBS clearance. Does the current project require DBS clearance? *Discuss this matter with your supervisor if you unsure*	NO

1.3	Does the study involve ANY of the following? Cl*inical populations; Children (under 16 years); Vulnerable adults such as individuals with mental or physical health problems, prisoners, vulnerable elderly, young offenders; Political, ethnic or religious groups/minorities; Sexually explicit material / issues relating to sexuality*; *Mood induction; Deception*	**NIO**
1.4	Is this a resubmission / amended application? *If so, you must attach the original application with the review decision and comments (you do not need to re-attach materials etc if the resubmission does not concern alterations to these). Please note that in the case of complex and voluminous applications, it is the responsibility of the applicant to identify the amended parts of the resubmission.*	NO

By submitting this form you confirm that:

- you are aware that any modifications to the design or method of the proposal will require resubmission;
- students will keep all materials, documents and data relating to this proposal until completion of your studies at Middlesex, in compliance with confidentiality guidelines (i.e., only you and your supervisor will be able to access the data);
- staff will keep all materials, documents and data relating to this proposal until the appropriate time after completion of the project, in compliance with confidentiality guidelines (i.e., only you and other members of your team will be able to access the data);

- students will provide all original paper and electronic data to the supervisor named on this form on completion of the research / dissertation submission;
- you have read and understood the British Psychological Society's *Code of Ethics and Conduct,* and *Code of Human Research Ethics.*

2 Ethical questions – all questions must be answered

2.1	Will you inform participants of their right to withdraw from the research at any time, without penalty?	YES
2.2	Will you provide a full debriefing at the end of the data collection phase?	YES
2.3	Will you be available to discuss the study with participants, if necessary, to monitor any negative effects or misconceptions?	YES
2.4	Under the Data Protection Act, participant information is confidential unless otherwise agreed in advance. Will participant anonymity be guaranteed?	YES
2.5	Is this research or part of it going to be conducted in a language other than English? *Note, full translations of all non-English materials must be provided and attached to this document*	NO
2.6	Is this research to be conducted only at Middlesex University? *If not, a completed Risk Assessment form - see Section 8 – must be completed, and permission from any hosting or collaborative institution must be obtained by letter or email, and appended to this document, before data collection can commence. If you are conducting an online survey or interviews via skype or telephone whilst you are at Middlesex University you do not need to fill in the risk assessment form.*	NO

If you have answered 'No' to questions 1, 2, 3, 4, and 6 above, please justify/discuss this below, outlining the measures you have taken to ensure participants are being dealt with in an ethical way.

I hope to conduct my interviews on the Middlesex university Campus Hendon. Although I am currently in discussion with Middlesex regarding this possibility, I have not yet got final confirmation. I hope to provide a letter of confirmation from Middlesex shortly. In the unlikely event that another location must be used this would be a suitable counselling room in an organisational setting where administrative staff are present. I have therefore completed a risk assessment form to prepare for either outcome.

Please see attached risk form that addresses any issues that could arise regarding question 2.6.

Are there any ethical issues that concern you about this particular piece of research, not covered elsewhere on this form? If so please outline them below

My interviewing is unlikely to cause my participants harm, however, I recognise that the sensitive nature of the interview material could cause them to become emotional. As stipulated in my proposal I will address this by checking in with my participants throughout the interview process. Should a participant become upset I will stop the interview immediately, arrange for a friend or family member to collect them and

remain with them until this person arrives. I will also provide information for support services as part of my debriefing process.

I will be interviewing women about their experience of mothering. In the very unlikely event that a child protection or welfare issue should arise, I would discuss any concerns immediately with my supervisor and follow the recommended safety procedures.

Before beginning interviewing I will clearly define the parameters of confidentiality, explaining that any information that may cause concern regarding safety of self or others would need to be shared with relevant professionals.

3 Research proposal

This section should contain sufficient information to enable the ethics committee reviewer to evaluate the ethical status of the research. ***A research proposal would normally be around 2 A4 pages in length (about 800 words) excluding references and additional materials.*** *The headings below are indicative, and you may choose whether or not to use them.*

Please find research proposal attached.

Aims and Hypotheses/Research Questions

Please refer to page 10 of proposal

Supporting literature and rationale

This section should include a brief discussion of previous research in the area which justifies your choice of topic, aims, hypotheses and research questions

Please refer to page 11 of research proposal

Method

The four sub-headings under method (design, participants, materials and procedures) should contain details about the design, participants, recruitment (including how and

from whom will informed consent be obtained), provision of information and, where necessary, deception.

Design

Please refer to page 22 of proposal

Participants

Please refer to page 22 of proposal

Materials (if appropriate)

N/A

Procedures

Details of the procedures, and what the participant will experience as part of the research are critical.

Please refer to pages 22-24 of proposal

Analysis

You should also include some discussion of how the data will be analysed.

Please see page 19 of proposal

References

Full references and ***any materials developed or adapted for this research*** *should also be included (this includes but is not limited to questionnaires, rating scales, and images). If due to the addition of these materials your file exceeds 3 MB, or if materials*

cannot be scanned for copyright reasons, they should be clearly identified in the research proposal. You need to provide references for Questionnaires which have been previously published/validated.

4 Information sheet

SEE DOCUMENT 'INFORMATION SHEET PSYCHOLOGY GUIDELINES FEBRUARY 2014' FOR FURTHER INFORMATION ABOUT HOW TO CREATE AN INFORMATION SHEET. THE TEMPLATE BELOW IS PROVIDED TO GUIDE YOU, DELETE GUIDENCE NOTES AND ONLY INCLUDE YOUR INFORMATION SHEET WHEN YOU SUBMIT YOUR APPLICATION

Psychology Department

Middlesex University

Hendon

London NW4 4BT

Researcher's name (or names), and the date.

Study title Is the title self-explanatory to a layperson? If not, a simplified title should be included.

Invitation paragraph e.g. "You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully, and discuss it with others if you wish. Please ask if there is

anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part."

What is the purpose of the research? You should explain the reason why participants' co-operation is requested, i.e. the background and aim of the research and why it is important.

What will happen to me if I take part? How long will the participant be involved in the research? Describe exactly what will happen. State where the research will take place (e.g. at Middlesex University). Briefly and simply mention what research methods you intend to use.

What are the possible disadvantages to taking part? Any risks should be explained to the participant.

Consent The form should state that the participant will be given a copy of the information sheet and asked to sign a consent form prior to taking part in the research. The information sheet should include the statement "Participation in this research is entirely voluntary. You do not have to take part if you do not want to. If you decide to take part you may withdraw at any time without giving a reason."

Who is organising and funding the research? If the research is being organised or sponsored by an external body (e.g. Medical Research Council) this should be stated.

What will happen to the data? Explain about: anonimyzing data; using data as group data only; publication / dissemination in scientific contexts or in dissertations which are in partial fulfilment of your UG/PG degree.

Who has reviewed the study? You must include “All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The Middlesex Psychology Department’s Ethics Committee have reviewed this proposal.”

Concluding section At the end of the form, thank your participants for reading their information sheet. **The information sheet must finally contain the institutional contact details of the researcher - your university email address, plus details of your supervisor (full address, email and office telephone).**

5 Informed consent

Middlesex University School of Health and Education

Psychology Department

Written Informed Consent

Title of study and academic year:

Researcher's name:

Supervisor's name and email*:*

- I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.

- I have been given contact details for the researcher in the information sheet.

- I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from the project at any time without any obligation to explain my reasons for doing so.

- I further understand that the data I provide may be used for analysis and subsequent publication, and I provide my consent that this may occur.

_____ _____

Print name Sign Name

date: _____

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Health and Education Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: _____

6 Debriefing

SEE DOCUMENT 'DEBRIEFING SHEET PSYCHOLOGY GUIDELINES FEBRUARY 2014' FOR DETAILED INFORMATION ABOUT HOW TO CREATE AN INFORMATION SHEET. THE BRIEF INFORMATION BELOW IS PROVIDED TO GUIDE YOU, DELETE GUIDENCE NOTES AND ONLY INCLUDE YOUR DEBRIEFING SHEET WHEN YOU SUBMIT YOUR APPLICATION

Psychology Department

Middlesex University

Hendon

London NW4 4BT

Researcher's name (or names), and the date.

Study title

A full debriefing should 'provide the participants with any necessary information to complete their understanding of the nature of the research' (Ethical Principles for Conducting Research with Human Participants, BPS Code of Conduct, Ethical Principles and Guidelines, p. 8). As a researcher you are obliged to 'discuss with the participants their experience of the research in order to monitor any unforeseen

negative effects or misconceptions' (op. cit.). Debriefing does not just involve telling the participant about the research, or handing them a sheet or a paper with a description of the research on it. This is provision of information rather than debriefing, and although providing the participant with information is an important part of the research process, it should not be confused with debriefing. Although as a researcher you are generally obliged to offer a full debriefing, your participants are not obliged to accept it.[1]

At debriefing, the researcher is recommended to encourage participants to get in touch if they had any further queries – this may be mentioned in a simple debriefing sheet, summarising the essential points of the research participation. The participant will be thanked for her/his contribution.

The debriefing sheet, if used, must contain the institutional information, study title, researcher and supervisor details and date.

[1] *Should a participant leave the research in distress, you should attempt to sensitively discuss with them the reasons for this. If this is not effective you should inform a senior member of staff immediately.*

7 INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following field/location work situations:

1. *All field/location work undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).*
2. *All field/location work undertaken by postgraduate students. Supervisors to complete with student(s).*
3. *Field/location work undertaken by research students. Student to complete with supervisor.*
4. *Field/location work/visits by research staff. Researcher to complete with Research Centre Head.*
5. *Essential information for students travelling abroad can be found on www.fco.gov.uk*

FIELD/LOCATION WORK DETAILS

Name:	Romy Shulman	**Student No** **Research** **Centre:(staff only)**	M00475227
	Dr Charlotte Macgregor	**Degree course**	DCPsych

Supervisor:			

NEXT OF KIN Telephone numbers and name of next of kin who may be contacted in the event of an accident	**Name:Ronnen Shulman (Husband)** **Phone**: 07968 376 248
Physical or psychological limitations to carrying out the proposed field/location work	None
Any health problems (full details) Which may be relevant to proposed field/location work activity in case of emergencies.	None
Locality (Country and Region)	United Kingdom
Travel Arrangements NB: Comprehensive travel and health insurance must always be obtained for	Local public transport/private care

independent overseas field/location work.	
Dates of Travel and Field/location work	July 2016 - July 2017

PLEASE READ THE FOLLOWING INFORMATION VERY CAREFULLY

Hazard Identification and Risk Assessment

List the localities to be visited or specify routes to be followed **(Col. 1).** For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern **(Col. 2).**

Examples of Potential Hazards :

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders.

Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

1. LOCALITY/ROUTE (specify here the exact name and address of each locality/organization)	2. POTENTIAL HAZARDS
Private meeting rooms/ therapy rooms at Middlesex University Campus, Hendon. This is to be confirmed shortly. Letter of confirmation to follow.	Lone working

The University Field/location work code of Practice booklet provides practical advice that should be followed in planning and conducting field/location work.

Risk Minimisation/Control Measures PLEASE READ VERY CAREFULLY

For each hazard identified **(Col 2),** list the precautions/control measures in place or that will be taken **(Col 3)** to **"reduce the risk to acceptable levels",** and the safety equipment **(Col 5)** that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 3),** categorise the field/location work risk for each location/route as negligible, low, moderate or high **(Col. 4).**

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

Examples of control measures/precautions:

Providing adequate training, information & instructions on field/location work tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs). **Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility.** Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of field/location work area.

Examples of Safety Equipment: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

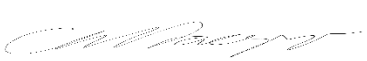
3. PRECAUTIONS/CONTROL MEASURES	4. RISK ASSESSMENT (low, moderate, high)	5. SAFETY/EQUIPMENT
Interviews will only be conducted where administrative or security staff are on sight, and contactable by both interviewer and participant. I have previously worked in the Middlesex counselling rooms and I am aware that administrative staff and security are present and easily contactable on site. I would also ensure that this is the case should any other location need to be used. Next of kin and NSPC will be notified of precise location and time of interview. A set time for a post interview phone call will be arranged in order to confirm the researcher's safety. A mobile phone will be carried and accessible at all times. Locating panic alarms if present.	Low	Mobile phone Panic alarm if present at location

Campus security contact number will be saved to speed dial. Wearing suitable clothing that is unlikely to cause offence.		

PLEASE READ THE FOLLOWING INFORMATION AND SIGN AS APPROPRIATE

DECLARATION: The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the field/location work period and additional precautions taken or field/location work discontinued if the risk is seen to be unacceptable.

Signature of Field/location worker (Student/Staff)	Click here to enter text.	**Date:**	Click here to enter a date.
Signature of Student Supervisor 	Click here to enter text.	**Date:**	16/05/16
APPROVAL: (ONE ONLY) **Signature of Director of Programmes** (undergraduate students only)	Click here to enter text.	**Date:**	Click here to enter a date.
Signature of Research Degree Co-ordinator or Director of Programmes (Postgraduate)	Click here to enter text.	**Date:**	Click here to enter a date.

Signature of Research Centre Head (for staff field/location workers**)**	Click here to enter text.	**Date:**	Click here to enter a date.

FIELD/LOCATION WORK CHECK LIST

1. Ensure that **all members** of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:

☑ Safety Knowledge & Training?

☑ Awareness of cultural, social & political differences?

☑ Personal clothing & safety equipment?

☑ Suitability of field/location workers to proposed tasks

☑ Physical & psychological fitness & disease immunity, protection & awareness?

2. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed with regard to

☐ Visa, permits?

☐ Weather conditions, tide times and ranges?

☑ Legal access to sites and/or persons?

☑ Suitability of field/location workers to proposed tasks?

☐ Vaccinations and other health precautions?

☐ Safety equipment and protective clothing?

☑ Financial and insurance implications?

☐ Travel and accommodation arrangements?

☐ Health insurance arrangements?

☐ Arrival times after journeys?

☐ Civil unrest and terrorism?

☑ Emergency procedures?

☐ Crime risk?

☑ Transport use?

☐ Political or military sensitivity of the proposed topic, its method or location?

Important information for retaining evidence of completed risk assessments:

Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the field/location worker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

RP/cc Sept 2010

8 1st Reviewer's decision

Click here to choose a decision

For Revise and Resubmit decisions, particular attention should be paid to the following:

☐ Section 1 details incomplete ☐ Clarity of Research Proposal ☐ Risk Assessment
☐ Professionalism and presentation of participant documentation (information sheet, informed consent, debriefing)
☐ Completeness of ethical approval form (individual questions requiring clarification may be identified here)

Additional comments from Reviewer 1:

Click here to enter text.

FOR DOUBLE REVIEW ONLY – Reviewer 2

Click here to choose a decision

For Revise and Resubmit decisions, particular attention should be paid to the following:

☐ Section 1 details incomplete ☐ Clarity of Research Proposal ☐ Risk Assessment

☐ Professionalism and presentation of participant documentation (information sheet, informed consent, debriefing)

☐ Completeness of ethical approval form (individual questions requiring clarification may be identified here)

Additional comments from Reviewer 2:

Click here to enter text.

11.3 Participant information sheet

New School of Psychotherapy and Counselling
61-63 Fortune Green Road
London NW6 1DR

Middlesex University
The Burroughs
London NW4 4BT

Participant Information Sheet

Researchers name: Romy Shulman

Date: 29 April 2016

Project Title: Using trauma as a lens to explore the experience of mothering a very premature infant in the first year after hospital discharge

Invitation

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

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What is the purpose of the research?

This study is being carried out as part of my studies at NSPC Ltd and Middlesex University. Very little research has been done on what it is like to be a mother to a very premature baby after the baby comes home from hospital in the first year. There are also not many services available to support mothers of premature babies during this time. The aim of this research is to get a better understanding of what it is like to be a mother to a baby born between 28 and 32 weeks of pregnancy during the first year after hospital discharge. By understanding this experience better, it may be possible to point out ways that support could be provided for new mothers who are having similar experiences in the future. It may also help to suggest what kind of services would be most useful. You are being asked to participate because you have replied to my advertisement for mothers who have given birth to premature babies between 28 and 32 weeks of pregnancy, where the infants are now aged between 3 and 5 years, to volunteer for this project.

What will happen to me if I take part?

You will be involved in the research process for approximately 1 hour. During this time I would like to interview you about your experience. The interview will take place in a

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meeting room suitable for a confidential discussion, and will last approximately 45-60 minutes. This will be all that will be required of you. At a later stage I will use a

qualitative research method to extract the main themes of what you and other people tell me about your experience, known as IPA, to reach some conclusions about my study.

What will you do with the information that I provide?

The interview may be transcribed by another person. So I will not use your full or last name in the interview and the person transcribing the interview will not know who you are. I will be recording the interview on a digital recorder, and will transfer the files to an encrypted USB stick for storage, deleting the files from the recorder. All of the information that you provide me will be identified only with a project code and stored either on the encrypted USB stick, or in a locked filing cabinet. I will keep the key that links your details with the project code in a locked filing cabinet.

The information will be kept at least until 6 months after I graduate, and will be treated as confidential. If my research is published, I will make sure that neither your name, nor other identifying details are used.

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Data will be stored according to the UK the Data Protection Act and the Freedom of Information Act

What are the possible disadvantages of taking part?

It is very unlikely that talking about your experience of mothering your very premature baby would cause you harm. However, talking about personal experiences may be distressing. If you feel distressed, please let me know, and if you wish, I will stop the interview. Although this is very unlikely, should you tell me something that I am

required by law to pass on to a third person, I will have to do so. Otherwise whatever you tell me will be confidential.

What are the possible benefits of taking part?

There is no intended benefit to the participant from taking part in this study. Being interviewed about your experience of mothering your premature baby has no direct benefit, either, although some people may find it an opportunity to reflect on their experience, and could find this beneficial. It is possible that some people might enjoy sharing their experience.

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Consent

You will be given a copy of this information sheet for your personal records, and if you agree to take part, you will be asked to sign the attached consent form before the study begins.

Participation in this research is entirely voluntary. You do not have to take part if you do not want to. If you decide to take part you may withdraw at any time without giving a reason.

Who is organising and funding the research?

This research is completely self-funded

Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC research ethics sub-committee have approved this study

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Expenses

If you think you may have difficulty getting to the interview, or arranging childcare please let me know.

Thank you for reading this information sheet. You will be given a copy of this participant information sheet, as well as a signed copy of the consent form to keep.

If you have any further questions, you can contact me at:

NSPC Ltd. 61-63 Fortune Green Road

London NW6 1DR

preemieparentresearch@gmail.com

0044 (0) 20 7624 0471

If you any concerns about the conduct of the study, you may contact my supervisor:

Dr Charlotte Macgregor

NSPC Ltd. 61-63 Fortune Green Road

London NW6 1DR

admin@nspc.org.uk

0044 (0) 20 7624 0471

11.4 Informed consent form

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The Burroughs
London NW4 4BT

Informed consent

Middlesex University School of Health and Education

Psychology Department

Written Informed Consent

Title of study:

Using trauma as a lens to explore the experience of mothering a very premature infant in the first year after hospital discharge

Academic year: Year 3 of Doctorate in Counselling Psychology

Researcher's name: Romy Shulman

Supervisor's name: Dr Charlotte Macgregor email: admin@nspc.org.uk

- I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.
- I have been given contact details for the researcher in the information sheet.

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- I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from the project at any time without any obligation to explain my reasons for doing so.
- I further understand that the data I provide may be used for analysis and subsequent publication, and I provide my consent that this may occur.

_____ _____

Print name Sign Name

date: _____

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Health and Education Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: _____

11.5 Debriefing sheet

New School of Psychotherapy and Counselling
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London NW6 1DR

Middlesex University
The Burroughs
London NW4 4BT

Debriefing Sheet

Psychology Department

Middlesex University

Hendon

London NW4 4BT

Researcher: Romy Shulman

Supervisor: Dr Charlotte Macgregor

29 April 2016

Study Title: Using trauma as a lens to explore the experience of mothering a very premature infant in the first year after hospital discharge

Thank you so much for giving your time to participate in this study. Should you wish to discuss any details of this study further, or if you have any further questions, please contact me at preemieparentresearch@gmail.com.

You may also find the following contacts and resources useful:

Local therapy options:

Free therapy: (Depending on participant's area) local NHS, local Bliss services

Low cost therapy: (Dependent on area)

Private therapy: The following link will show lists of accredited therapists in your area:

http://www.itsgoodtotalk.org.uk/therapists

Useful websites:

https://www.bliss.org.uk

https://www.tommys.org

Support groups

https://www.bliss.org.uk

Peer support

https://www.facebook.com/lifeafterNICU

8.6 Transcript for participant 1

Ok. So if I can start by asking you, what were the initial days and weeks like for you after you brought home your baby after hospital?
Uumm, tt, surreal, ha, I guess, um, we came home very suddenly. Um, erm, they told us that he was going to be in until his due date, and then at 34 weeks, they suddenly said “he’s fine” um they going to uuhh make sure that breastfeeding’s established this weekend and you’ll be home probably by Sunday. This was on the Friday. So we hadn’t even

Gosh, Ok

Ok? Hadn’t even made 35 weeks yet. Um, and yes he came on the Sunday. Hahaha so…And I actually had to phone my husband and say uh “you know you thought you were coming to visit us…”

Hahaha

Haha, you’re actually picking us up

Um, so umm, the, I think, erm, I...it’s kind of a…a... writ large version of anybody’s first isn’t it you know your sort of bring them home and think what am I supposed to do with them? But you bring them home and you really thinking what I am supposed to do with them. You’re kind of, the thing being, though but that because you’ve been in hospital you’ve kind of fallen through the cracks, so the um, special care unit doesn’t want to know you anymore, postnatal doesn’t want to know you anymore. Because I will still ill as well.

Erm, The health visitors aren’t, don’t know anything about premmies…or they certainly didn’t, in my hospital. Um, you kind of, you know, all your questions, you sort of, have nowhere really to turn to. Breastfeeding was complete hell. Um and nobody knew a thing about it. Erm, so um the, and the thing was that he was born in July. He was, he was due in September, he was born in July. So it was summer. So everyone was on holiday from work, so there wasn’t anybody around. Erm, so it was just kind of limping through and um, he lost weight for the first two weeks. And he came and said “he’s a

premmie, he's too tired. He told me all the wrong the things about, I know now, he's too tired to um, to feed, so you need to stop. Yes but he's hungry eh, yeah so um, it was just sort of. I can't entirely remember, the first weeks to be honest, other than thinking I have to feed him, and um…

That might be what the first few weeks were, you know

And of course,

What your focus was

Yes and of course you'll know this, you can't, they're not allowed to go more than three hours at night without feeding.

Yes, yeah,

A…and, so…

And and so, sorry it's a boy or a girl?

It's a boy

So if he wasn't feeding or if he seemed too tired to feed that must have been quite stressful for you.

Well, uh, the thing was that because he came home before, you know the suck reflex kicks in at 35 weeks, and he came home before that

Yes

He didn't have the suck reflex when he came home.

Right

He probably, he couldn't do the, even the breath swallow suck. Just couldn't do it. He could do one of the three but he couldn't do all three of them, um so it really really was a struggle

Yes

Because he didn't know how to put everything together. Nobody knew how to help. Um, we got a consultant, she didn't know what to do either. Um, uh, so we kinda limped on until 4 months and then gave up and gave him bottles and it would take an hour and a half to feed him…a 90ml bottle. So of course by that time it was time to start again. So think actually the first few months were just feeding him. A lot. (Sigh). Yes.

And for the few months following that as he started to grow and develop can you remember how you experienced those next few months,

Well certainly, cert, certainly weaning, was you know, we, um um at that point, um, for the first time I did ring bliss just before actually and they said to me ah do it at 5 months, its fine, and so I did, "and he went oh is this what life's about and I don't think he's stopped eating since (chuckle)

Laugh…ok

Ya and he's now 98th centile, for his his

Wow. Ok. So he's done very well

So yes. Um… we started going out um there was a um, one of the local children's' centres actually had a group for prems. Uh, that they started up, um, it wasn't terribly well advertised, there always only about 2 or 3 of us

Ok

Um each time.

And this Hospital also apparently had one that they did in conjunction with Bliss, but it all got terribly political, um… uh so it it all got very confused and uh the children's centre suggested that they amalgamated so that there was more but they refused to do that and sigh,

Amalgamate as in join the

The two groups together so that there were more

Ok, but all for premature

Yeah

Babies only

Yeah. Um, and it was, it was all very odd, um but I did I did sort of, that was once a month, I did religiously go to those for a little while.

And did you find that it was helpful for you to go…well you carried on going so

Um, yeah…yeah…it was quite nice that it was a small group as well, and also you know you sort of just after something like that that you hehe, talk about it quite a lot and, it's nice to talk about it with people who don't go 'ooh there she goes again kind of, or don't get it

Is that, is that, is that how you felt? … That when you spoke about your experience that is was uh, people you know, didn't understand that, why you were still talking about it or…

…Yeeeah, um, I mean it's not the…the the people who say it's a wonderful experience are kind of in the minority anyway aren't they? You know there's, there are a lot more horrendous experiences out there than people like to admit, even in the full term, and the natural birth and all the rest of it…

Mmm

Erm, but I think there is a little bit of a taboo isn't there? That you're not supposed to kind of talk about it past a certain point

Why do you think that is? Why did you feel like that?

Um…well in part, in part I think it's because of the adjusted age so you're always slightly behind, so everyone else that you're kind of going on with and onto the next stage, but you know you're still, still waiting. Although I have to say he decided at, you know, he did grow and everything at the correct age,

Ok

Um, you know he was on his feet at 10 months

Wow, walking?

Yeah, we booked back to New z when he was one because we though, ah, it'll be fine, he's a prem, he won't be walking, you know, that's 10 ten months adjusted…I spent the entire 24 hours I think walking up and down,

Oh boy…

Running after him up and down, after him up and down, the isle of the plane. Yes

So tha, so in terms of your experience of those few months of development, for you, um, I guess it must have been like a pleasant surprise that he was actually developed on target for what would have matched his original due date…is that?...

Yeah, cer, certainly there were the, the other thing that happened quite a lot in the first year was because I come from a family on both sides, my husband's family and my family are very much in education there was a lot of doom and gloom you know he's going to struggle and he's going to be behind and he's going to sort of you know, and

there was one member of the family that refused to acknowledge that he was… um, born in July. You know, they refused to acknowledge his real age. Um

What was that like for you?

Ha ha, um, euuus, so it was, uh, we just about made it through talking to each other, and were just about still talking to each other. Err, um, cos I said to him you know, hang on a second I was there, on the 18th of July. I was there. Um, err… so, um, but you know sort as he grew and sort of started meeting milestones that kind of tailed off. But of course nobody ever said oh we were wrong look he's doing fine, it's just that, you don't talk about it anymore kind of…thing

Okay. And that must have been quite hard before he started meeting his milestones to have as you say with your family from the education background knowing what might have happened, what could happen when a baby's born early, um, to carry that negativity for you, before you seen how things were going to turn out.

Well it's interesting because actually erm, I knew he'd be fine. Bizarrely because I had 2 miscarriages before M and the minute I could see m I knew this one would be fine. I knew he'd be early, I didn't know he'd be that early, I knew he'd be fine, so it was just like you know, what are you talking about? He IS going to be fine.

So you had a strong I guess kind of mother's instinct that um, you knew you could tell from your baby that he was going to be okay?

Well this is the baby in NICU who you know they put him in the, he had Pneumothorax the after birth so they had to drain that twice, um…

That's just to put a

That's fluid

Yes that's around the lung, in the in the cavity ya

Um, but uuh, you know he was the

Um they stuck him in the incubator and he actually minus 8 weeks he actually wriggled himself down out of the nest and kicked the bottom of the incubator. So all these other prem babies are lying there nice and neat and prem and he's kicking 'I think he's gonna be fine'

Right so you could see some strength

Yes…..yeah

…ok

…eeeeh, yes. I dunno, uum, (pause) ….it was an odd time…

An odd time did you say?

Yes

Can you say a bit, a bit more about that, about the odd time?

Well I suppose for me, the other thing being that for me my entire family is on the other side of the world. So and um we're both older parents and my husband's an older of older parents because they had 7 miscarriages before they had him. So it took them ten years to, to conceive him. So there was kind of no one.

So you didn't have a …a support system really?

No. and so, not having a support system in the system as well, you know, I felt, completely erm, sort of completely lost really. I mean the whole breast feeding thing was really big actually for me. I sort of. That felt like a total failure. Um, took me quite a while to get over that one, that I only made it, mixed feeding to 4 months.

So that, it made you feel like a failure for not being able to breastfeed

Yeah

Um And it wasn't until a long time afterward when somebody said, do you know that the majority of prem babies don't get breastfed
Ya…ya

That actually the majority of full term babies don't get breastfed to 4 months even…um…

But there's quite a lot of pressure around it isn't there?

Yeah…well ye, the, this was this was they, you know they, they they, it was very pressurising at the hospital and in NICU BUT they had no clue how to help me because he didn't have….because he could suck on a dummie but of course you don't have to swallow

Right

When you're sucking on a dummy, that somebody pointed out to me a long time later as well. You know that's, okay that's good he's got the suck reflex going but it's a lot more complicated than that isn't it.

It's the coordination isn't it?

Yeah

Of of the 3 together isn't it?

Yeah um, and the the one, we had….I can't remember I think she was a la leche, erm, I can't remember where we got the consultant from…uuum and I realised after she had told me everything wrong about it, um she said "oh he should be getting all he needs in 7 minutes, you're doing it wrong he's, hasn't got everything in minutes umm

She actually said to you you're doing it wrong

Mmmm yeah and so we went back to the hospital but
By that time the breastfeeding consultant had come off because he was about 2 or 3 months old. Um we wrote back and said look can we see the breastfeeding consultant. She came and sat down and said "are you sure that subconsciously you actually don't want to breastfeed and that's why it's going wrong?"

That must have been so frustrating for you to hear that.

I was like yeah that's fine we've come all the way back to the hospital paid the fine, brought my screaming child in cos I really don't want to.

And it sounds like you were really doing you best you know doing everything that you could

Yeah, I think, well everything I knew to do

Mmmm

And and then um actually we did find the one thing um thing that uuuh first year, um, between well uh from 7 months to about 18 months he had gastro-enteritis 9 times. Um which brought on the… lacto allergy, lactose allergy, which it often does. Um He probably had a cow's milk protein allergy any way um but it took, cos he was still under the paediatrician, so he still went to the paediatrician, um…who… he he he, he, one time cos he just didn't sleep, he was a dreadful sleeper, he screamed all night, erm, quite often. Um, cos of course he was lying down, and you know even if you sat him up still because he was still and because he was inactive it was really uncomfortable for him. And of course we were on formula by this point

Right

Um…err, but I've gone back and read the old threads on mums net and just every day on mums net 'no sleep last night just screamed' I had, had, casually forgotten about

how (laughing) bad that was. Um but again the paediatrician he was, um, I got called a hysterical mother once, I got told I was trying to medicalise my child. You know he obvious', you know, he can't be a-allergic to anything because he's growing eh

So you were coming in with things that you had had seen as a mother, you could see that there were issues that you were concerned about, but it doesn't sound like it was taken seriously

Not until, no, not until 18 months when finally, I said it was dairy, that it was a dairy allergy. Um, so in the end I just took him off, everything. Um, it was quite hard to do that on your own under one, because of course you have so many milks you can't give them under 1 right. You can't give them nut milk, or rice milk, or any of those, but I finally just did it and everything went away. And they went, "oh, maybe he, maybe he has a dairy allergy Yes that's what I've been saying for about 13 months, something like that".

Mmm. It sounds, I mean, through the the the few bits that you've talked about, and not having your family here to support you, it sounds like it was quite a lonely…

Yeah it was. I think um, cos I think this sort of for the parents of babies that are in hospital that's a whole set of horror and all the rest of it, and but there's then the sort of the next set when you're kind of ok, um, to then just leave you to it, because they're so overstretched they have to just put it on the babies who really, you know,, who really need their attention. And he was okay, he was at home, he was growing and he was you know, I walked him in the door to the paediatricians appointment holding onto my finger when he was about 9 months old actually, um you know, so they looked and they "he doesn't need us" which in one way he didn't. Um…

Mhmm. But did they look at you, and to see whether maybe you needed them

Oh I'm very good at…looking as if I'm okay. Cos I, somebody said to me you need to go in and cry I said Oh I'm really bad at doing that. I can't cry on tap. I go in and do strong, kiwi woman, so they go oh no she's fine as well. And if you say actually no Im not coping, they look at you and go no but you just strung a sentence together you're

fine, you're not crying on me. Women cry when they're not coping so, go away, you're alright

Okay. So so, there's something about being strong, being able to be there for your child, kind of equalled that you didn't need any support.

Clearly…I mean, my hospital is quite fairly, a, there are some quite deprived populous, and so the health visitors are quite busy. And I know that when the health visitor walked into my house, um, you know, and I have a supportive husband who was amazing. You know, she looked and went okay, Im so up to my eyeballs, I'm going to go and do all the things that I really desperately have to do because they will at least survive. And I get that, I, I do not…

There's something about like a comparative need really that you might have needed help but there were certainly people who maybe needed more help

Mmm exactly

And the idea of the babies in the NICU needing more help because that's life threatening at that moment. So that even even though they may have been recognised there was a need it just wasn't as great as other needs that needed their time

Yes

And that is maybe just part of the public health issue in general

Yes

Ok, um Im just going to have a look at my few questions here. Um, Well I guess we have sort of touched on this a little bit already, but, how did your experience in that, those few months, affect your feelings of being a mother?

Oh I still don't think Im one! I still still look at him and think 'Im your mother? Really? Except at the moment were going through the 'I'm not your friend' stage sigh, okay, I won't play with you then…I didn't mean you're not my friend

Hahaha

Um, I've found out a really good way to annoy him now as well. I say, I know Im the worst mother in the world, trademark! He says I hate it when you say that. I say I know that's why I say it.

Ha ha ha ha

Um, yeah, yeah, it, eh, I sa I, it took me a long time to feel like mum at all. Er, and it took me a long time to feel like he was mine. It sort of, cos I think that's sort of a, that's part of the um, part of the NICU experience, yes you don't quite feel that you have any authority at all. Cos everyone else is doing everything. This hospital there were some awesomely wonderful nurses in there, and there were some that weren't quite so awesomely wonderful. Um, and it is 4 years ago, I think things have changed a little bit already actually in 4 years. Um, but you know you're sort of, they they, tell you you're allowed to change a nappy, they tell you you're allowed to do it, that you can feed, you know and you you never quite sure what you're allowed and then you get home and you're still thinking what am I allowed to do? Well, wha…what is this? And then of course there's kind of the, you've nearly lost him so you're just kind of waiting, to make sure that you're actually gonna keep him, I think, as well. …so

Ya, maybe a difficulty in uh, in adjusting to that, that you know, when you've lived with the idea of possible loss

Yeah, so you just yes, I mean certainly, it's interesting, my husband still, has to go check he's breathing at night. I don't quite so much, although last night because we've all got colds, and he's coughing and it was really loud, then all of a sudden it went dead silent and it's just aw, just go and check.

Because he also had the, uh, the apnoea, the prem apnoea for quite a while. Uh and of course they say you know, don't worry until it's over 20 seconds. It a really long time 20 seconds isn't it

Yeah

Um so, and he didn't lose that until he was about 10 months, literally
So,

And how often did that used to happen to him

Um several times a night

Oh several times a night

Oh really

MMMYEAH

So how was that for you?

Oh I kind of did get used to it. And ok well start counting, cos also it decreased, you know when it started it was like 18, 19 seconds, and we were thinking oh 2 more seconds we have to do something about this. Oh no he's breathing again. Um I also learned, cos they said this, they said go and breath really loudly next to him, um and the, and it has to be the mother who goes and breaths, and that will…kick it off again. And after a while it seemed to, it didn't seem to, I don't know what, in the first, but it did seem to later, it sort of reminded him to breathe. So, I, he was he, I kept him in with me until 8 months, and then he was such a dreadful sleeper that I KICKED HIM OUT TO HIS OWN ROOM after that.

What was that like for you, being, like you say it had to be the mother to be next to him um helping to regulate his breathing? Im just think of that statement alongside this

feeling of you know finding it hard to believe that you were his mother. You know, and doing that exercise that only his mother could do for him to help him breath.

Ha ha. Um yeah, I remember, I've never had any difficulty in thinking about the sort of things that you tend to do to keep him alive. I always thought that that was kind of my job in a way. Was kind of, except that I ff..it felt like acting the role I think, sort of, fake it till you make it, yes?

So like the

You act like a mother until you hopefully, at some time, Im still waiting, feel like one…yes, he was a very um, interesting actually. He's, uh, he loved kangaroo care right from the beginning. Um, that was one of the things they weren't, they didn't quite understand at my hospital. Some of them did and realised you know you do it for as long, and as much, and some of them said oh no he's a prem, just an hour at a time because he'll get tired.

Mmm

So they I don't know whether it was, I know how, I didn't think it was particularly new at that point cos I think they'd been doing I tin Australia for, for a time but I don't know. Some of them obviously didn't um now I've gone and done full research and read, I didn't know then. Um, but he's always, always right in the beginning. I didn't actually put him down for the first 4 months at home

At home you were holding him all the time

Yeah yea, I slept with him on me, which I know you're not supposed to do but I sort of propped myself and put him in a way that hopefully was okay. He would not be put down, and he would go to his dad either. He would every so often, but but at night it definitely had to be me.

That must have

Like right from the beginning and I remember the day I put him down and he went to sleep. It was so amazing

Mmm

He was 17 weeks

Gosh

…and um,

It must have been quite demanding on you to…

I put him down and he went to sleep. I was like “he’s over there!” yeah. Yeah. But he, he remained and still actually remains a very very affectionate and physical child. Um, so, I think actually probably I spent most of the um, first two years of his life with him on me if I was in his company. I went back to work when he was 9 months old. Um, he went to an awesomely wonderful childminder, um, who he he’s only, he just left when he went to school. Uh, he’s, she’s kind of his second family really. Um, but, and I was supposed to work full time but um, because he as ill, you know, of course the whole thing, if you have diarrhoea or throwing up that’s another 48 hours that you can’t go.

Mmm

So he’d be ill for like 3 days so it would be a whole week.

Right

So this is the, this is the really wonderful part of the whole thing. Where I work I have the most understanding line manager in the entire universe. And my, I was probably off work 50% of the time until he was 3. And they said, we know you do your work. That’s fine, do whatever you need to do to keep him ok, keep yourself okay, just

Mmm

If, ye, get, you get the work done and if you don't we'll do it for you kind of, so... I did have extraordinary support from work actually um…

They mu…

That I never felt my job was on the line or…that they were even annoyed that I wasn't you know…even for you know really important things like interviews, where they're very short staffed and there were a couple of days I had to be off which meant the rest of them had to run round like with heads without heads….not a word…to make me feel bad about that

That sounds uh
Yeah

Like very important support. Because I suppose, you know there comes a time, well there comes a time as always that you know the rest of your life, responsibilities, go on,

Yes

At the same time as you know bringing this child home and…

Yes

It all has to happen together

Yes. Cos, my er, at that point um, my, my husband was a school teacher. So of course he couldn't really, it was a lot more difficult for him to take any time off.

Right

Because of course they had to get supply in. So it actually cost them money. In a way it doesn't cost the university money at all, because all that happens, if I can't take a class it doesn't get caught. Um, and you kind of make up tutorial times later and all the rest of it. Um, they cover it, they don't get somebody in, whereas of course if a teachers off they cost the school money. So they have to put a limit on it. I, I get that. So it kind of, while it kind of looks and it still looks as if we still have a very gender stereotyped household, it's simply I have the flexibility

Right

And the supportive line manager

Right

That makes that possible and

Because it puts a lot of responsibility

Yeah

Uh, on you, you know if your husband couldn't take off work and, if your job was also important to you, and, you know you balance everything to you know together, a balancing act

Yeah. I mean the one thing, the one thing at work that didn't, and this is probably entirely off the subject; you know ref? Um, all research institutions go in for research excellence framework, so you have to put I loads of stuff or you have to have a certain amount of research output. And the university is funded according to er, how good your research is per staff member. And up until this last round, they do this about every 5 years, and up until this last round if you're full time you're supposed to put in 4 research hours. So 4 articles or 4 books. A book and an article have the same weight which is ridiculous. Um, and if you're on maternity leave you get one taken off, so I should have had 3. And then you can apply for a reduction, one more reduction if

something horrendous happened, for a whole lot of circumstances, and I thought I think Im going to apply hand in another reduction. And they wouldn't because they said it wasn't bad enough.

I brought in all the medical stuff. You have to go into fairly graphic details. So I gave them all the graphic details of the birth. I was ill for 6 months afterwards. He was ill for 18 months, and all the rest of it and um, apparently it wasn't bad enough, in black and white

No what was that like for you to go through?

That one I cried. Hahahaha. I managed to walk out the room before I cried….especially when two men tell you…that what you've been through…

It seems like you've had quite quite a hard time with outside, you know people outside really no understanding what what you've been through and what you were going through, just not quite getting it…

I suppose also when you have you kid with you, you know as they said…

Sorry you were saying if you have a kid who looks…

You know, as the paediatrician said, you know, he was, I mean he's always been really strong and he's really muscly, and you know the frames always there, kind of skinny and he never put heft on, but he kind of put on muscle, um, I remember giving him to a friend to have, you know she wanted a cuddle with this lovely cute baby so she'd hold him and try to juggle this kid whose all over the place and taking off at five months, down the road, and completely muscly. She said oh he's, kind of sinew isn't he…yeah…so you know, it looks okay, he he, he is okay, it's it's as you as you kind of said, you know did I cope? But he was probably better than I was at that point…yeah

But I think maybe that's that's part of it, the, I mean, um, they are you know, better, they are better, he was better, he was well, from, from the experience in NICU and he was growing and developing, but at the same happened, you had been through this

trauma with him, you weren't well yourself at times, this trauma had and, and, and, maybe that is part of it. That other people look and see a well baby, and you

So you should be over it…

No they don't see what you've gone through

Yeah yeah, yeah

We did have the one thing, I mean, his his childminder was wonderful but um, uh, uh, he's kind of turned her into the, the um, the borough expert on prems so she has this little queue of parents of prems who want to…

Oh ok

Cos she kind of gets it now, but it did, she she had a bit of a learning curve as well, because of course the thing about having a ten month old that walks but is 8 moths adjusted he has the risk assessment of an 8 month old, in other words none whatsoever, even less than a baby who does walk at that age. Right? Um, and he also…sort of emotionally and mentally he did have the delay, um, so, people see this, you know, he he really shot up, by the time he was 7 months he he was born on the 24th centile but the time he's 7 months he's 75th centile, he grew 12cm in three months. He still does that. Um so you know he he looks, he he he looked, and of course he is physically able so everyone assumes that he's the age, slightly older.

Right

Cos they still do it. You knows he's 98th centile. He's summer born, they're expecting him to have that kind of emotionally maturity of an older, and I know that sou…emotional maturity sounds the wrong thing to say about a ten month old but uh…

No I know what you're saying…I understand

Um, so you know, you know a 10 month old, he was, if you picked he was still pulling hair, um and, he, he'd get really frustrated. He also, he spoke very very late, he was nearly three when he started talking. He was so frustrated

Mmm

At not being able to say what he wanted. For a while it was okay cos he's a real communicator so you know, he wa, wanted something that was fine. But he got to a stage where he wanted to express more complicated things and he couldn't. And he knew that other children younger than him were better at this than he was. …Um, but even at about 1 he got, he knew there was a way of doing this and he couldn't do it. So he was, and he was in pain the whole time because he had this allergy that nobody he he he, so, and it often comes out of course in aggression in kids, right. Um so you know he was having these horrendous melt downs and everything, and she was saying ah you've got a real problem with aggression. I said, well aggression, Im not gonna call an 11, 12 month old aggressive

Mmm

Um, so we we had a little bit of, you I felt I had to defend (laugh) him on that one, um, you know and once she realised everything…

Who's she?

Um, the childminder okay

Um, But he was sort of starting to get a label of, you know he was the difficult one, and not just, not just the childminder but sort of generally as well, that he was sort of difficult and, you know they start bandying labels around, and you go hang on a second…maybe, but he's 12 months old. Shall we just wait a while and see

Yeah

You know

And I suppose that that you know maybe that connects to the connect, the the corrected age idea as well, that 12 months old really was

10 months, yeah yeah

So it's hard for other people to to see that maybe and

And that was the o…that was one of the times the paediatrician actually was really really helpful because he, cos um, I told him all this tha the you know child minder was worried about and he kind of laughed and said, he's thinking like a 10 month old. He has no clue that when he runs straight down there it's maybe not the best idea because you're probably going to crash into that wall at the end. He has no clue. A 10 month old might have a little bit more of that perception, but he's 8 months, he's not gonna…so just say, go and tell her…

So that was very useful I thought

Okay, so there were some times that he was quite supportive

Yeah

And maybe the knowledge was helpful I guess

Yeah

But it must have been quite frustrating for you as well, frustrating that you know, he couldn't express himself, that, you know, that, you were the one answering to his needs a lot of the time that, I imagine that must have been quite difficult for you as well, to maybe not understand what he wanted or….I mean I might wrong

Oh yeah absolutely. I was, I was very good at translating, I have to say, to the point where he now has to say to me mum, I'll say it ha aha

Hahaha

So aw yes, sorry about that son

Okay

Um, err, uuuh,

So you could understand him

Oh I could, and he Also we were signing a little bit. When we could, when he wasn't ill. Um
And he got a little bit of that

Okay

And he, he enjoyed that so

And how did you feel about the fact that he wasn't talking yet

That one worried me for a very long time, uh, at the 2 year review, um, you know they give you that little list, um, of all the things they were supposed to do, and the physical things tick, all the way, and then you get to the emotional bit and talking and all the rest of it it's like, none of it. That was one of the, that time, um, I got one of the older more experienced health visitors who I had never met before who did his um, who did his review, and you know he was uuuh, I mean he babbled a lot. Um, and I said to her I had these, I had these concerns, and the childminder wrote a letter as well so she…cos Id said to her, I had, we need to do something about it, so she wrote a letter. And the health visitor just sat and looked at him and then she laughed and said, "He doesn't need to talk. He's communicating in every other way possible. Don't, don't worry yet, he he when he needs to talk he will".

Mmm

And the other thing being, and uh, wh, when I talked to my mother about it she said oh yeah your sister, um, cos I have two sisters and the first one did the whole you know did the whole talk by words, saying a word every so often and all the rest of it. She said no, no, but your second sister heard everyone else talking in sentences and decided that's how you talk.

Mmm

So, um, she tried to do sentences, and of course it was a bit of a disaster and you know whatever. And I realised actually Matthew was doing the same thing as well. That he was trying to say everything, so he wasn't, he did go for the you know, point and say ball, he was trying to say 'aw, Id actually like you to pass me that ball please" and you know, and Im going but you know and it was just gobbledegook

Mmm

Until he could, cos the reason I think I was worried as well was because he didn't have the suck reflex properly, and of course there's the link between… I had no worries about his language. It was very clear cos he could understand everything that was said, but I knew, that mechanically there's a link between the suck and learning to actually… But to be honest he's not entirely clear yet. He's not as clear as most 4 year olds. But I'm not worried.

MMM

And he's actually getting clearer now he's in school so…ha, I'll try and stop doing the motherly anxiety thing…
Sigh

But that's a bit part of it isn't it, the motherly anxiety. That's it. That's that's what's you know, what's there during that first year

Yeah

So, it sounds like in a way, uh, we were saying earlier that the, the practical things kind of went onto an automatic mode. That you didn't find it hard to do the practical things as you said to keep him alive, and to take care of him, um, but its sounds a bit like that was maybe separated from the bonding side

Yeah

ERM, SO, Im wondering if you have uh, I don't know any thoughts about the bonding

I've thought, Yeah, I've thought about that quite a lot cos I actually I I I don't, I don't think I'm, it's probably slightly exacerbated by the fact that I don't think I'm particularly a baby person. So you know, you get through the baby bit. You know I've always said, I wish I could have taken maternity leave at 1, cos, I just think they become awfully interesting at 1, whereas before that's kind of, they cute,

Hahaha

But, um, I don't find babies terribly interesting to be honest. Um, even mine hahaha

Hahaha

Um, so yeah so Im not entirely, I do remember, I absolutely with clarity remember the first time he smiled at me properly. He was about 4 months old. That's a long wait isn't it? When you have a premmie. For that first smile. And I I I, we were, were sitting in the car in the Sainsbury's car park, and he just turned, I had him on my lap, and he just looked at me and he went, sort of this look of recognition came over his face and he just grinned at me, and I though ah, ah, maybe having a baby's not that bad after all

Hahaha

You know, the baby bit, isn't, isn't that bad after all. Uum, but the the, yeah, Im not sure I did bond particularly in the first year. It was always sort of…I don't think

he…would know that though. …..um, I don't know, what's the definition anyway…I, its, its, cos this one I've thought about a lot, cos I have been upset with people of course…

What's the definition of bonding with a baby?

Because you know, I would have fought anyone tooth and nail to keep him, and keep him alive, from birth, Im still not sure…so, yes…I don't know

Some kind of a feeling I guess that you have that was, that something tells you that you don't think you bonded in that first year

Yeah, yeah not entirely

Im wondering if its

Well, yeah, is its, but I've kind of wondered whether I had slightly um, rose coloured expectations in the first place, and whether, whether I didn't, or whether I just didn't meet my own slightly uh, over the top expectations what mothers are supposed to feel for this baby in the first year of life.

Can I…would you share that with me, what it, if if you remember what your rose coloured expectations might have been?

Well the thing about being, I was 42, when he was born, so I was a very old mother. Um, so I don't think you know, and everyone says to you, oh, it's gonna, your you have no idea what's coming, you know, it's gonna be so tough. There is nothing that surprised me. You know, I knew, I know you had sleepless nights and I know blblblblb. It was all…. Um, having said that however, I did have little things like I thought I'll just put him in the, I'll be able to just put him in the mo….I'll be on maternity leave. I'll just put him in the moses basket, he'll go to sleep, I can play the piano, and I can get back into playing again. ….yeah, um, still not playing. Um …much. Um, but yeah so it is… I think my rose coloured expectations were about uh, what feeling motherly is about. Um, so I, cos Mumsnet, Mumsnet's great. We had a, we had um, a running midnight thread. So while I, we used to chat while we fed in the middle of the night, which was

great. Um, and then we had one for older mothers as well, I was on, um for the over 40s, geriatric mums, um. And on both of them kind of saying, you know, you'd sort of slink onto the thread, and guilty, saying I really feel like screaming at him tonight cos this is just too much. And they all go yeah, it's part of being a mother, you want to scream every so often, you didn't, its fine, so. You know, you get the feeling that you should always love your children, and…smile serenely….really not hahahaha. Uh…You know that kind of "Im never going to shout at my children, ever" yeah

So, so the reality of being a mother wasn't quite the same as your idea of, fee, of what you thought the feeling might have been like

Oh what I, what I was supposed to feel to be a good one yeah.

Okay, so the reality was different from uh, what you thought you might expect to feel

Yeah

And you found support in that from the other midnight mums

Yeah exactly

It didn't seem to be news to them, what you were feeling ha ha

Er yes, exactly I wasn't the only one

Yeah. Yeah. Ya, so it sounds like you got a lot of support from the online groups and and the peer support

I think I would have probably quite literally gone nuts without them actually

Okay so that was really

They were sort of the, the one place I could…

That was an important factor. And was this other um, I know you've said some of them were premmie mums. I know your support group was um, premmie mums specifically and the net mums, was that also mainly premmies

There was one other, there was one other on the midnight thread. Oh, actually no um, there was one in the, ohm 2, there were 3 of us. Matthew was 31, there was a 34 week and a 35 week as well.

Okay, so, so there was common experience also with the full term…mums with full term babies, on that thread as well, and then some premmie ones

Yeah

Okay. Okay. Um, ….if you look back, what would you say, if anything, hahaha, did you find easy, about, about that time?

(Long Pause) um, this might sounds really odd, ahaha…playing with him. Um, cos he was he, he was curious from the minute…we have this wonderful photo of him at 2 minutes old, at 31 plus 1, he stole the thermometer that they doing the Apgar form, so they had it under there, and he, and he's holding it…and he, he became a celebrity.

Hehe

And that kind of sums him up. You know he can't leave anything alone. You know so, even minus 8 weeks trying to breastfeed him we had to put a screen round him. Everyone thought it was for my modesty, no it was because he would just, you know

Hahaha

Ah look over there…you're not supposed to do that…um, so he was always, he always actually, when he wasn't feeding or asleep, for about 2 minutes a day, ha ha, but he wanted quite a lot of stimulation right from the beginning. Which was the really fun bit. It was fun

Mmm

You know he's one of the few babies ever who just loved tummy time. We used to stick him down on his tummy um and he was very into, you know he just loves…stuff, so that was easy…

So it was easy to be with him, play with him. It sounds like that's the way that you connected with him

Yeah, I suppose

I suppose that play time is uh, is the stress free time maybe. You not

He's not screaming haha…I'm not screaming…yeah

Yeah. And it's also the time when um, nothings really expected of either of you

Yeah

You don't have to feed him, he doesn't have to eat, he doesn't have to sleep, you don't have to sleep, and it was just…you know, time to be together

Yeah

So I uh, cos when you started off saying that uh, that it might sound odd. But really when you think about it it's not odd at all. I suppose that you know, that could be seen as the best bit you know, everybody's just…being

Yeah…I guess. I suppose you do the other two so that you get that one really, don't you. We eat and sleep so that we do everything else

Yeah yeah, the nice bits. And I, I, you can correct me if I'm wrong, but I noticed before that you also said before that you found it easy to, to do the practical bits. You know, that they would you say that that, I don't know

But as in knowing what I was I supposed to do, yeah. Yeah

But it being, okay yeah, I hear you. But being there obviously wasn't easy. I don't think any mother can say that uh, looking after their child, the practical bits is always an easy

It's not easy easy to wake up at 3 o'clock in the morning when you've been awake at 2 o'clock, and 1 o'clock

No absolutely not

And at quarter to midnight and just ya

A bit of both there I guess.

Yeah

Um, I don't know if there's anything else that you, that you would like to share. Something that sticks out for you? I mean I, I put a few questions together but I'm sure I haven't covered everything and Im just wondering if there's anything important, you know, that you feel is important to share, you know that maybe we've not talked about

Uuuh, no, I think, I can't think of anything …else

Its eh, It doesn't sound like it from what's come up but uh, did you access any emotional support like as in, therapy or counselling, during during those few months,

Uh, I have actually before for eh, for other reasons and I went back, probably after he was one.

After he was one

But that year I didn't

Do you think that that had any significance, the fact that he waited until after he was one?

Well I just waited because I thought, he would just scream for the whole time. Uh, when I said that to her she just said ‘Pff, Im a mother, I don’t care, you could have brought him’.

So part of the issue is that you would have had to have taken him with

Yeah

To therapy

Yeah

That’s something to think about I guess. For new mothers during that year

Yeah. I mean they offered, they they offered counselling, in the hosp, sort of vaguely offered counselling in the hospital. But um, I think it was very very clear actually post birth, that I did need something um, but um, they were a bit… yes, I certainly think um, that maybe they should be a little bit more proactive. I don’t know what it’s like kind of globally, but that hospital certainly were a little bit um,
“Well you just do it, and you get on with it, don’t you, because look at all these other parents in NICU that are just getting on with it. And they probably weren’t either.

Mmm

Um, and they sort of vaguely at some point said do you want to talk to somebody, and by that time I’d, you know I’d had this breastfeeding consultant say tut, you know maybe subconsciously you don’t. Would like to go reread your Freud, cos you are, I think you are….but anyway...um

So that uh, you saying that that put you off maybe

Yeah yeah, put me off completely. It did

Yeah

Right. So this was, if it was already after the breastfeeding consultant then you were already home, so this wasn't during the NICU that you were offered the counselling. It was afterwards

But to be honest I might have been offered because, but I don't remember it

Okay

And even the times having total meltdowns in the parent room in NICU nobody, I'm pretty sure nobody offered.

Oh really, even when you were on the NICU

Yeah

It sounds like there was a huge expectation on you to just pull it together and carry on. And it sounds also like they implied that well, everybody else is pulling themselves together and carrying on and so should you. Is that your?

Yeah

It sounds like that was your message?

Yeah

Well it sounds like you took it on very well actually…he he he

Yes

Hehehe

You, I mean it sounds like you really did and you were really you know, soldiered on, sounds like. You know, there for your son, 24 hours a day. Uh, and I mean Im glad to hear that after the first year that you did uh, access some support for yourself. And Im thinking that that, you know, um, I don't know if that has something to do with it maybe? That, in that first year, that a mother is really there, a mother of a premature baby especially, is just there primarily for the baby, and thinking much more about the baby than about themselves. Do you think that that would be an accurate kind of thing to say? Does that resonate with you?

Yeah yeah

And when things settle down, then you kind of went off to think about well actually maybe I need some, some support as well

Yeah, cos also of course by that time I was back at work. So I had that time of the day when I didn't have him. So it was just easier.

Yeah, a bit of time for yourself

Yes. Which I think is a treat for a preterm mum.

Yes

Is there anything else that you would like to add?

I don't think so no

Would you be okay if we, if we stop there?

Yeah

Thank you so much, thank you. Im going to switch this off.